DEAFNESS AND MENTAL HEALTH: PERCEPTIONS OF HEALTH WITHIN THE DEAF COMMUNITY

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A dissertation submitted to the University of Bristol in accordance with the requirements for the degree of Doctor of Philosophy

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MEMORANDUM

I certify that this dissertation is my own independent work and has not been presented previously for any other degree.

Signed: ..... Date: 16.12.98

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ABSTRACT

A high rate of mental ill-health is known to exist within the deaf community. While deafness alone is not intrinsically linked to psychopathology, the experience of being deaf in a hearing world is a salient factor. The deaf community is now recognised as a cultural and linguistic minority, with its own worldview based on collective experience and long-standing beliefs. Cultural perceptions of mental health within the deaf community remain unexplored, and constitute a gap in an understanding of wellness and illness behaviour.

This thesis explores the issues arising from the cultural experience of deaf people which creates deaf wellness. The approach taken is multi-perspective involving both deaf and hearing people and both quantitative and qualitative methodology.

These studies explored the incidence of mental ill health within a cohort of deaf people, now in their mid thirties. The first study discovered a much higher rate of referral to specialist psychiatric units for the deaf, in the cohort (Study 1). The second study showed an increased incidence of mental ill health in a sub-sample of those unknown to the psychiatric units. Interviews with the sub-sample (Study 2) used the GHQ-30 and SF-36 standardised health assessment scales, and open-response, semi-structured interview, respectively. Normal frames of reference were found to obscure a full understanding of wellness behaviour within the group.

Focus groups in the deaf community explored cultural perceptions of deafness and deaf wellness (Study 3). Deaf wellness was described as a process, often necessitating a cultural transition to the deaf community, and as a maintained state, characterised by positive coping and 'insider' identification with other deaf people.

Study 4 considered the context within which deaf wellness evolved. Interviews with former welfare workers and social workers for deaf people identified the socio-cultural climate within which deaf people developed perceptions about deafness and deaf wellness. This professional group exerted unique constraining power over deaf people, which prevented the expression of deaf-defined wellness. Resistance to such expressions of cultural dominance constituted one key motivation to deaf wellness.

Finally a model of deaf wellness is proposed consisting of 6 key features, which comprise a culturally appropriate lens through which to understand mental health within the deaf community. The value of this model lies in the fact that it offers a new interpretive framework within which to appropriately understand mental health within the deaf community.

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Sign language This term will be used to describe language that may include more features of English than BSL

SSE Sign Supported English. SSE, is understood to mean sign language which more closely resembles English structure than BSL.

TC Total Communication – see section 1.5.

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Chapter 1 Deafness and the Deaf Community: Developmental Pathways

1.1 Deaf Community

1.1.1 The deaf community from the outside

Attempts at defining the deaf community have been deeply enmeshed with how deafness itself has been perceived. When deafness is equated with deficiency (the *lack* of hearing) or deviancy (from the normal state of hearing), the deaf community is regarded simply as a collection of people who cannot hear. This view supposes that association between deaf people is motivated primarily by the inability to deal with others. That is, without the communication skills required to move within the hearing world, companionship must be sought among those similarly 'afflicted', who must resort to primitive sign systems for communication. Within this model of the deaf community, a deaf person possessing verbal communication skills would have little need to associate with other deaf people:

> If a deaf person had a profound loss and had failed to attain acceptable speech and lip-reading skills he/she would become a member of the deaf community. If on the other hand he/she had attained such skills he/she would not become a member. The belief was that, being able to communicate with hearing people, he/she would have no desire to associate with other deaf people (Hynes 1988, p6).

As Walsh (1981) suggests, deaf people's handicap in communicating with the hearing world often 'limits them to the world of the deaf' (Walsh 1981, p164). Associated with this model is the belief that sign language is little more than a primitive, albeit functional, means of communication between those who cannot hear.

As Baker and Cokely (1980) point out, such definitions of the deaf community arise from hearing society's values and understanding. As such, they have been described as the views of those 'outside' (Baker, Cokely 1980) the deaf community.

From the earliest documentation, the experiences of deaf people have been narrated through their relationship with hearing professionals, as teachers, guardians or pastoral carers. Although many early deaf clubs or 'associations' were established by deaf people

themselves, hearing professionals, representing the Church, were instrumental in the formation of many associations. These associations became the bastions of deaf culture and community.

The involvement of the Church was rooted specifically in an ecclesiastical concern for the welfare of the spiritually, educationally and socially 'impoverished'. Thus, the fundamental goal of welfare work was to provide for the needs of deaf adults in the way that asylums and schools for the deaf at the time were attempting to provide for the deaf child (Lysons 1963).

The first association in the UK was set up in Edinburgh in the 1820s, and was charged with catering for the 'spiritual, emotional, educational and physical welfare of deaf people' (General Synod 1997, p11). Eventually, the National Assistance Act (1948) made welfare provision for the deaf a mandatory and secular responsibility, and by 1952 the Deaf Welfare Examination Board had been set up, responsible for the training of welfare workers for deaf people. By 1962, the number of missions or voluntary organisations for the deaf had mushroomed from a small handful, to 104, in 57 different branches (Lysons 1963, p79).

Each association was staffed by at least one missioner or welfare worker, often aided by a 'lady worker', who in addition to co-ordinating welfare services also ran the deaf club. To many deaf people the missioner or welfare worker was an extremely important figure, and often the only hearing person who could communicate in sign language. Driven by the belief that deafness was 'savage and severe in creating isolation' (Corfmat 1990, p56) and consequently that deaf people were helpless and incapable of living independently as a community, the style of welfare work was, to say the least, involved:

> As the deaf are not able to enjoy, as do hearing people, all the advantages of what is called normal spiritual and community life, their social and spiritual needs must be met not only during the week, but largely at weekends, which means that those who serve them must be available the whole of Saturday and Sunday as well as

> most evenings, in addition to the normal day office hours which suit those deaf who prefer to attend in the day time (DWEB Publication[1] 1956).

Sustaining their role within the deaf community necessitated that missioners or welfare workers held strong views about deaf people and particularly deaf people's capabilities and needs. Some of these beliefs were formalised in the literature produced by DWEB. Informal channels of information operated with a similar goal to justify dependency on hearing professionals. For example, magazines such as Deaf Welfare, first published in 1956 contained anecdotes that were of a style that reinforced both a professional fraternity among welfare workers, and more significantly, a collective view of the deaf community.

Though some of the official responsibility of the Church was delegated to social services, the delivery of welfare services remained within the voluntary sector and unofficially continued to be practised by the clergy.

The founding of associations for the deaf was inspired by a genuine and profound belief that deaf people needed help. Different theories exist as to the impact of this professional relationship. While some writers draw out reference to resistance and challenges to accusations of deficiency among deaf people (e.g. Ladd 1988), others suggest that the very structure of the community was sustained through the relationship between deaf people and those charged with their welfare. One aspect of this can be seen in a study of the role of the clergy in the deaf community in America. Walsh (1981) describes the '*mutual* possessiveness' (my italics) between the two parties:

> ...the cleric seemed to 'own' the deaf, while the deaf community regarded the pastor as theirs alone...as shepherd of this small flock, the cleric may often have dominated the deaf, generally acted as their spokesman, and sometimes considered the deaf world his or her own territory...(Walsh 1981, p165).

Hearing professionals, predominantly those representing the Church, have consequently claimed a role in the creation of structures and situations where deaf people are 'taken care of' and as a significant outcome, the language of deaf people is protected:

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[1]Deaf Welfare Examination Board

> The Church in England, especially the Church of England...can take credit for the foundation of many organisations which care for the profoundly deaf people in their midst, and for the development of primitive social welfare services among them...the Church can also take credit that through these organisations, and the church services they offered, sign language was kept alive and at a high level through many years when much educational theory tried to deny it...(General Synod 1997, p12-13).

Much of the literature referring to the establishing of deaf associations and to the role of welfare workers is necessarily retrospective and outdated. However, more recently, accounts suggest that some aspects of the deaf community, particularly those pertinent to the provision of welfare, remain intact today. The following quotation from the Church of England General Synod Working Party Report (1997) on the provision of services to deaf people reflects present day beliefs within the Church of England as to the needs of the deaf community. One statement suggests a particular understanding of deaf people, and, for example, the rules of admission to the deaf community, quite different to that expressed by deaf people themselves:

> Because someone is profoundly deaf, it does not mean that they are automatically members of the deaf community. Being deaf gives them the right to be members, in the sociological and psychological sense, but does not mean that they are members, which is a matter of choice. For some this is a serious loss, as less adequate, less well-educated, less competent deaf people are in danger of being left out and alone in a society which is still an alien and hostile environment. It is appropriate for the Church to bring people together, in order to enable them to find a community and social base for their individual lives. In this way, drawing deaf people together becomes an act of pastoral care in itself, as well as an opportunity for evangelism and worship (General Synod 1997, p10).

Similarly, the following account conveys the message that the deaf community exists primarily to support otherwise isolated, and 'unloved' deaf people:

> Sign language can be read by anyone in a room so deaf people are more open in their conversations. Touch is an accepted means of communication among deaf people and many hearing people could learn from them how to reach out to those who feel lonely, isolated, unloved or unwanted by the world today (General Synod 1997, p52)

The suggestion throughout the report is that the Church still has a responsibility to create a situation in which deaf people may associate. It would not be strictly true to present this

model of the deaf community as resulting from the perception and paternalism of *all* hearing professionals. Nevertheless there is evidence that this view maintains some support (e.g. Langan 1991).

Social welfare workers, (later social workers), evolved primarily from this Church-dominated, professional heritage which in turn began with missioners to deaf people at the beginning of the nineteenth century.

Many accounts have described the power attached to the welfare worker within the context of the evolution of a professional role. Although this understanding has often led to a call for redefinition of the role of the social worker for the deaf (e.g. Hynes 1988), there is resistance to such change.

While several writers have documented patterns of resistance (Ladd 1988), or dissatisfaction (Hynes 1988) among deaf people, other accounts of the deaf community illuminate not only deaf people's compliance but their positive desire to be nurtured (e.g. Walsh 1981, Langan 1991).

1.1.2 The deaf community from the inside

The outsider model of the deaf community has been constructed primarily by hearing people to describe deaf people. Those deaf people who consider themselves members of the deaf community often have a different perception. To them, the deaf community must be constructed and defined not by hearing outsiders but by deaf people.

While deaf people define the insider perception, it is increasingly shared on an ideological level, by hearing people. Often referred to as the cultural or linguistic model, the deaf community is viewed as a minority group akin to ethnic minority communities, characterised by the existence of its own language and culture.

Theories on membership criteria are numerous, but most often necessitate a shared language, specifically sign language, and identification with other deaf people (Steinberg 1991, Meadow 1972). Hearing loss itself is not a defining feature, as many

audiologically deaf people are not considered members of the deaf community. The crucial feature of membership criteria is that deaf people themselves decide them.

The degree to which membership depends upon the use of sign language varies. Several writers (e.g. Carmel 1987, Kyle, Woll 1985) recognise that most definitions within the cultural linguistic framework regard the use of sign language as the most important identifying feature.

Higgins (1980), on the other hand, suggests that while communication styles cover a wide spectrum, attitudes, rather than a limited range of particular skills, define membership. As Higgins (1980) suggests, membership is 'achieved' rather than 'ascribed', and is achieved through identification with the deaf world, through the shared experiences of deafness and through participation in community activities (Higgins 1980). Similarly the deaf community has also been defined as constituting those possessing 'attitudinal deafness':

> The deaf community comprises those deaf and hard of hearing individuals who share a common language, common experiences and values and a common way of interacting with each other and with hearing people. The most basic factor determining who is a member of the deaf community seems to be called 'attitudinal deafness'. This occurs when a person identifies him/herself as a member of the deaf community and other members accept that person as part of the community (Baker, Padden 1978, p6)

Most definitions of membership are based on the belief that no one single factor determines acceptance (Baker, Cokely 1980). Membership is described as determined by a number of overlapping criteria that include hearing loss, the use and understanding of sign language, and the political and social involvement in community life. Within each component, centrality is determined by the strength of positive attitude, consequently, core members:

> ...are those who do not feel that deafness itself is a problem, who have early facility and pride in signing, who are seen constantly at social gatherings of deaf people and who enjoy the confidence of their peers...(Baker, Cokely 1980, p8).

Attached to an insider model of the deaf community is a celebration of difference, expressed in various forms as deaf culture. Deaf culture has been described as:

> …knowledge, belief, art, morals and law as well as the practices of members of the community. These are mainly mediated through language, so deaf culture, like all cultures, is carried through the language (Freeman, Malkin, Hastings 1975, p9)

While attempts have been made to define deaf culture, most suffice to describe various aspects of deaf people's lives that separate them from hearing society. As with earlier research into the behaviour of sub-cultures (e.g. Lunde 1956), attempts have been made to identify.

areas of behaviour which separate members of the deaf community from members of mainstream hearing society. The following extract provides a good snapshot of deaf culture:

> How can one describe the community's life in dry statistics and data? But, come to that, how can one describe it in words? Perhaps the bustle and laughter when deaf people get together and have the chance to use their language in full flow is best left to the imagination. Notable scenes in deaf culture include the standing joke of the club committee trying to push people out at closing time, and crowds standing around in the street signing for a good hour afterwards. Or of people of all ages staying up half the night together, telling jokes and stories (a major part of deaf culture), signing songs, or poems or playing sign language-based games. Or of a regional rally, where a town centre is taken over by sign language for a weekend, and people from all over the country greet old school friends across the street on their morning promenade (Ladd 1988, p35).

In contrast, many deaf people do not choose to pursue membership or are not accepted by the deaf community. Those who are not members of the deaf community typically have a lesser degree of hearing loss, often prefer to communicate using speech rather than sign, and describe themselves as hearing impaired, or partially hearing (Hindley 1997):

> Their common identity is less defined by a particular language and culture and more by their active struggle to overcome the disability that arises from their condition (Hindley 1997, p101).

In summary, two models of the deaf community are presented. The first has as its point of reference, the perceptions of hearing professionals, and the second constitutes an insider definition, maintained by deaf people themselves.

1.2 Sign Language[2]

Changes in the perception of the deaf community have been reflected in the treatment of sign language. Sign language had traditionally been thought of as an inferior system of gesture and mime, with no grammatical structure. The use of a primitive system of communication among deaf people corroborated the belief that deaf people were limited in their linguistic and cognitive capabilities. Sign language was something deaf people resorted to in the face of failing attempts at verbal communication. In turn, while sign language was thought to have little, if any, linguistic status, deaf people remained 'languageless'. The perception of the deaf community as a disabled group, has thus been swayed historically by the status of its' language.

> for its non-academic nature and lack of emphasis on English, sign language has been viewed by hearing people as epitomising the failing deaf person (Kyle, Woll 1985, p67).

Thus, much of the oppression of the deaf community has been expressed in the suppression of its natural language (e.g. Harris 1995, Padden 1980, Lane 1992).

> Language is simultaneously a store or a repository of cultural knowledge, a symbol of social identity, and a medium of interaction (Gumperz 1974, p12).

In turn, the recognition of the deaf community as a cultural minority group has been dependent upon the recognition of the linguistic component of its minority status.

Nowhere is the denial of sign language felt more strongly than in the field of education. Ladd (1988) provides a compelling account of the survival of sign language in the face of oppressive and inflexible oral policies. While sign language was banned in the classroom, beyond the watch of teachers, deaf children continued to sign to each other.

Ladd (1988) highlights the fact that pockets of resistance to the suppression of sign language (and therefore of the deaf community), have always been maintained. However, the ability of deaf people to resist the domination of its organisations by hearing people has been severely weakened by the decline in deaf literacy as a result of oralist education practices.

Research into sign language from the 1960s onwards (Stokoe, Casterline, Croneberg 1976, Klima, Bellugi 1979), confirmed that sign languages are indeed fully functional languages, with their own vocabulary, syntax and grammar (e.g. Kyle, Woll 1985, Loncke, Quertinmont, Ferreyra 1989):

> British Sign Language is a language of movement and space, of hands and of the eyes, of abstract communication as well as iconic storytelling, but most of all it is the language of the deaf community in the UK It is not a new language, nor is it a system recently developed by hearing people; rather it is a naturally occurring form of communication among people who do not hear. (Kyle, Woll 1985, p5)

Moreover, deaf children, given the right exposure, have a strong tendency to acquire sign language, and when they do so, linguistic development and information processing takes place quite naturally, albeit in a typically 'untypical' way. The natural sign language acquisition of deaf children of deaf parents has also confirmed this theory (see section 1.4.5).

In summary, sign language is both the focus of hearing people's oppression and deaf people's independence.

1.3 Structure of the Deaf Community

Unlike other minority communities, the one-generational nature of the deaf community exerts a profound impact upon both its structure and identity. Deaf people are born to hearing families (with a hearing cultural perspective) and, in turn, deaf people have hearing children in over 90% of cases (Kyle, Allsop 1982). Many deaf people from

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[2]The term sign language is used to refer to the language of deaf people, in a similar way in which 'spoken language' refers to the language of hearing people. BSL (British Sign Language) or ASL (American Sign Language) refer to the specific language of the country, equivalent to English or Punjabi for hearing people.

hearing families make a transition from the hearing environment of their parents to cultural affiliation with the deaf community. The transition is often described as a rite of passage to deaf people from hearing families (Lane 1992), often 'fraught with emotional and symbolic significance' (Lane 1992 p94), and likened to 'coming home' or finding a family (Padden, Humphries 1988).

Community association is primarily by peer group, rather than family. In terms of lifestyle, Hynes (1988) considers the dominance of peer group relations, a defining feature of the deaf community:

> These are often of primary importance and may last for sixty years or more (Becker 1980, p14)

Consequently, cultural transmission tends to be horizontal rather than vertical (except for the 5% of deaf people born to deaf parents). Deaf people tend to marry one another. A study of the deaf community in America in the early 1970s found that more deaf than hearing people remained single, but of those who marry, over 80% marry other deaf people (Schein, Delk 1974). Similarly in the UK, one study of 175 deaf people found 35% single (compared to 25% of hearing people), but of those who married, 92% had married another deaf person (Kyle, Allsop 1982).

Clearly the structure of the deaf community is unusual. The impact on the individual of transition between the culture of parents and the culture of a deaf peer group should not be underestimated.

1.4 The Experience of Deafness

The following section examines the experience of deafness, and specifically, some of the critical points at which this experience differs to that of those who are born hearing, and crucially, who are born into hearing families. The literature reviewed, for the most part, is based upon the experience of the 95% of deaf people who are born into hearing families. The development of the deaf child will be traced using a life span perspective.

1.4.1 Demography of deafness

Estimates as to the prevalence of prelingual deafness are in the region of 0.8 per 1000 live births (Newton 1985). A recent Social Services Inspectorate report (1997) estimated that 0.5% of the population (n = 250,000) had a profound hearing loss, and 0.1% of the population (n = 62,000) use British Sign Language.

1.4.2 Aetiology of deafness

Studies of the aetiology of hearing loss are numerous, however many confirm the finding that in approximately 40% of cases the cause of deafness is unknown. Factors most commonly associated both with conductive and sensorineural hearing loss are both congenital and acquired and may include rubella, cytomegalovirus, or perinatal disorders (Densham 1995). Approximately 5% of deaf children have deaf parents and together with this group, more still are deaf through hereditary causes (Kyle et al 1997). Consequently, over 95% of deaf children are born to hearing families (Kyle, Allsop 1982), most of whom have had little if any exposure to deafness prior to the diagnosis of deafness in their child (Goldberg 1979).

1.4.3 Diagnosis and adjustment

Upon diagnosis of deafness, parents are faced with a child who will experience and respond to the world in a significantly different way. Society transmits pervasive messages about this *difference*. Historically, attitudes and ideologies have revolved around the belief that the family is normal and the deaf child, is deviant (Henderson, Hendershott 1991, Scott 1978). Within the social construction of motherhood, mothers of disabled children fall outside the idealised notion of normal motherhood (Gregory, Bishop, Sheldon 1995). Although the mother is herself without the stigma of being deaf, she is bound up with the stigmatised person (Gregory, Hartley 1991).

Consequently, as Hindley (1997) states, the most prevalent model used to explain parental response is that of crisis/adaptation in which positive confirmation of deafness is expected to create feelings of loss. Responses to diagnosis have been framed within a 'grief

model' (Moses 1985, Goldberg 1979) or grief response (Schlesinger, Meadow 1972). in which parents grieve the loss of a perfect baby. Likened to experiences of bereavement, responses to diagnosis are thought to be in a series of stages, from shock, denial, grief and anger, to guilt realisation and ultimately acceptance (Kubler-Ross 1969). Moving autobiographical accounts of the experience of diagnosis allude to the trauma of the process of diagnosis and adjustment (e.g. Robinson 1991, Gregory et al 1995).

Vernon (1973) identifies certain factors that exacerbate the stress of the diagnosis period, for example the degree to which denial is used as a coping mechanism. Effects on the family can be both negative and long term. He observes that parent's denial of deafness leads to goals which are unrealistic, incongruous and unattainable, but which were nevertheless assiduously strived for. Based on findings from a clinical patient population of deaf people, Vernon (1971) goes so far as to claim that 'pathological coping' in families was the major aetiology underlying mental illness and less severe non-adjustive behaviour.

Within the family system, parents' initial responses are thought to have a longer-term impact on the family's accommodation to deafness and on the individual's perception of deafness. Interaction patterns within the family can be seen to represent a scaled down version of what the child can expect from society, which is often a message of deviance, inferiority and inequality (Henderson, Hendershott 1991).

Harris (1995) explores the notion of the 'family view' of deafness through interviews with nineteen deaf adults. Respondents tended to internalise perceptions such that deafness was a 'regrettable occurrence', 'a shame', and that the family was somehow 'incomplete' (Harris 1995, p35). Harris points out that the organising feature of each family view of deafness was the experience which occurred directly or immediately after diagnosis of deafness. In turn, any emotional response was deeply enmeshed in the parent's wish for perfection. Of particular relevance to this study were the negative 'family views' which were perceived to have a severe effect on the later formation of deaf identity in the child. This could be described as the internalised construction of deafness.

Upon recognition of deafness, parents are faced with a complex set of challenges that are both emotional and practical. From the outset, they are expected to negotiate a plethora of professionals, many giving conflicting messages (Gregory 1991). From the moment of diagnosis, parenting is no longer a private affair but is shared with many professional agencies, for example, audiologists, doctors or teachers, all claiming to know more than parents about their child. Schlesinger (1985) proposes that parents of deaf children experience a profound sense of powerlessness as a result of their inability to change their child's disability, the deaf child's lack of response to normal communication systems and professionals' undermining of their normal parental power.

Manfredi (1993) describes the range of maternal reactions to the recognition of deafness in a child and to the consequent relationship with the child and with professionals. Parental overall reactions range from maintaining a spontaneous relationship with a child, and taking the advice of professionals with flexibility, to the responses of those who are 'transformed into an expert's clone', teaching verbal language as if it were an imperative and interacting without spontaneity (Manfredi 1993, p51). The latter has been described in its extreme form as "surdo-centricism", and has been identified as an additional emotional barrier to the adjustment to deafness (Laurenzi 1993).

Events surrounding diagnosis such as the response of clinicians and how the news is broken, appear to have a contributory role in parents' longer term negative response (Danek 1988, cited in Hindley 1997, Vernon 1973).

An alternative view focuses on family coping and adjustment to a deaf child. Upon recognition of deafness, many parents experience relief at having deafness diagnosed, having suspected worse (Gregory 1991). Young (1995) highlights family attempts to retain integrity and cohesion in the face of the gradual realisation of the child's difference. According to her analysis, parents do not grieve in the sense of bereavement, and the family structures usually survive the realisation of the child's deafness. Likewise, Bond (1991) suggests that while a high incidence of emotional and behavioural problems exists among deaf children, the *majority* of deaf children and adults manage their lives

successfully, encouraged by a successful relationship between parent, professional and child.

1.4.4 Patterns of attachment

It seems likely that the attachment process between mother[3] and child has some differences for deaf children. Early research has tended to locate the problem with the child, citing the 'lack of audition' as the primary explanation for disrupted attachment:

> the child's lack of audition frequently yields a limited ability to communicate and apprehend that emotionality which is integral to the child's bond with his mother and a mode for the expression and development of love, closeness and individuation (Altshuler 1974)

While the baby is initially a passive player, satisfied that immediate needs for nurturance are met, it is clear that during early development this satisfaction becomes increasingly dependent on the quality of their developmental environment (Altshuler 1974).

A large body of literature (e.g. Winnicott 1988, Stein, Jabaley 1981), documents the long-term outcome of the quality of early infant attachment, but dwells on the role of language and communication, rather than audition.

John Bowlby devised a series of stages of attachment. His work is particularly relevant in that it pinpoints one key period at which language and communication become essential. The transition from Bowlby's (1969) Stage III to Stage IV Phase of attachment relies on verbal communication between mother and child:

> A developmental change in communication skills provide the vehicle for a qualitative shift from Stage III to Stage IV attachment (Marvin 1977, cited in Greenberg, Marvin 1979).

The third stage of attachment is characterised by verbal communication about plans. This facilitates the transition to Stage IV, characterised by a 'goal-corrected partnership', at

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[3]Phoenix (1991) justifies the near universal treatment of the mother as opposed to the father as the primary figure of attachment for the infant. She states that since research by Winnicott and others in the 1950s and 1960s, when fathers were accepted as periphery to the primary bonding process, there have only been minor shifts in parenting patterns.

which point both mother and child operate in an intentional fashion to construct and carry out joint goals and plans (Greenberg, Marvin 1979).

A study of 28, 3-5 year old deaf children with hearing parents revealed that the level of communication was highly correlated with the ability to communicate about objects and events not physically present, and thereby the attainment of the Phase IV partnership (Greenberg, Marvin 1979).

1.4.5 Communication and language development

Articulation of social and emotional experiences through words and sentences is the key to social relationships. Socialisation patterns may be seen to be dependent on the quality of early and continued communication within the family. Although much of the initial bonding process is non-verbal, for children and adults to extend and elaborate their shared experiences and establish shared meaning, they must be able to participate and communicate at the same time (Ritter-Brinton, Stewart 1992).

Returning to the experience of the deaf child, a necessary though not sufficient requirement for adequate development is the availability of a shared communication system within family. Research has demonstrated deaf children's significant language delays (e.g. Hadadian, Rose 1991). This has been attributed predominantly to the effects of relatively late diagnosis of deafness (rarely within the first year) and/or a limited or inadequate early language input from parents (Spencer 1993, Gregory, Hindley 1996).

Outdated beliefs that the acquisition of language is obscured by deafness itself have been discredited by comparative studies of sign language acquisition in deaf children of deaf parents. Similar rates of language acquisition were found between deaf children acquiring sign and hearing children acquiring speech (e.g. Volterra 1986), and very similar patterns of linguistic and social interaction between deaf mothers/deaf infant dyads and hearing mothers/hearing infants dyads (Meadow, Greenberg, Erting, Carmichel 1981). Initial research pointed to deaf children reaching the milestone of producing their first sign before hearing children produce their first word (Schlesinger, Meadow 1972).

While one theory states that natural gesture occurs in both deaf and hearing infants but is interpreted as an emergent sign in deaf children, further research has taken one more step. Current theory suggests that sign language modelled by parents, advances the experience of signing from deictic gesture (pointing) to referential gesture and other research has noted deaf children's early ability to combine referential gestures (Volterra, cited in Kyle, Woll 1983).

Upon diagnosis of deafness, many hearing parents are advised not to sign with their deaf child, in the belief that manual language prevents the development of speech (Ladd 1988, Archbold, Robinson 1996). Research has demonstrated that due to its richness and structural complexity, sign language is actually a highly appropriate language base. Additionally, sign language has the capacity both to give the child access to representational skills (Harris 1978), and to fulfil the psychological criterion of giving the child a language which can operate as an internal code (Harris 1978).

The success of hearing parents' use of signs in their communication with their deaf child is not straightforward often being dependent on factors such as the style and quality of input, attitudes towards deafness and the existence of wider maternal support systems (Gregory, Hindley 1996). For example, although using a relatively small sample of seven deaf children, diagnosed by 7 months and observed at various points between 9 and 18 months, Spencer (1993) found that the rate at which infants acquired signs was directly related to the frequency with which mothers used signs expressively. Additionally, one of the main factors associated with the signing performance of the mother was the degree to which other adults around were also learning and using sign language.

While many researchers define a rich language environment for deaf children as characterised by the early inclusion of sign language, a minority of studies report a positive outcome from the oral method. Manfredi (1993) from her study of 25 deaf children brought up in an oral programme in Italy, found that a positive attitude towards deafness and the *flexible* use of oral communication were the major determinants of positive psychosocial development in childhood.

In the past, the existence of language deprived or 'languageless' deaf people spurred research into the impact of such languagelessness on psychosocial development (Furth 1966). While it is now claimed that deaf people have the same capacity for language as hearing people, delays in language acquisition, and concerns about quality of language have sustained interest in the effects of deafness on psycho-social staged theories of development, primarily those of Erikson (1968) (e.g. Kennedy 1990).

Erikson maintained that the whole life cycle could be thought of as the resolution of eight critical phases. In order to achieve each new level of development, the individual must acquire a balance between eight pairs of psychosocial 'extremes'. Schlesinger (1978) considers the effects of deafness on the resolution of the first three critical stages identified by Erikson: 'basic trust versus mistrust', 'autonomy versus shame and doubt', and 'initiative versus guilt'. Her conclusions were based on hearing parents who predominantly, and often ineffectively used speech to communicate with their deaf children. As language becomes an increasingly important component, the deaf child of hearing parents was less able to resolve or find a balance to the crises signifying each critical phase. For example, in seeking to strike a balance between 'autonomy' and 'shame and doubt' (Stage II), many deaf children found meaning in being either emphatically obedient or defiant (Schlesinger 1978). As one might expect, better overall functioning was identified in those children of deaf parents whose first language was ASL and, to a lesser degree, parents who used a combination of speech and sign.

From the literature above, it is unsurprising that theories of deaf child development have converged on belief in the direct and disruptive effects of a weak language (and thus communication) base. Liben (1978) offers an alternative interpretation. She proposes that the inferiority of deaf subjects in a range of cognitive and social tasks is only indirectly a result of language deficiencies, proposing that deaf people are *experientially* deprived and consequently deficient. She sets this theory in a Piagetian framework, considering the four 'causal agents of development': maturation, experience with objects. social experience and equilibrium. The deaf child's environment is examined with respect to each factor. The need for effective communication is outlined, and perceived

to be indirectly connected to cognitive performance through 'experiential' interactions with family, peers, teachers and society in general.

1.4.6 Early interaction patterns

Socialisation patterns in later life often have roots in childhood interaction experience. Research into interaction behaviour between mother and child highlights the sensitive blend of influences and resources that shape the deaf child's early environment. This review does not permit a comprehensive account of all areas of research, however one aspect of interaction will be considered which has relevance to later self-concept, that is. research into maternal control.

Studies of hearing mother/deaf child interaction with hearing child control groups have observed a higher frequency of interaction in the former group, with an associated increase in maternal directiveness or dominance. For example Wedell-Monnig and Lumley (1980), in a study of six deaf children and six hearing children (aged between 13.2 - 29.2 months) and their hearing mothers concluded that mothers of hearing impaired toddlers initiated interactions more than mothers of hearing toddlers. They hypothesise either that mothers who are aware of their child's deafness flood their child with stimulation to compensate for sensory loss (accounting for over-controlling behaviour), or that the child demonstrates learned helplessness having experienced that his or her behaviour has no effect on the environment.

It becomes clear that maternal attitudes and behaviour, in turn are dependent on a number of other variables. Ainsworth's original work on attachment and early interaction (Ainsworth, Blehar, Waters, Wall 1978) stated that the quality of the relationship between mother and child is more dependent on maternal than infant characteristics. In the case of deaf children and their mothers, factors such as maternal social support (MacTurk, Meadow-Orlans, Sanford-Koester, Spencer 1993) influence early interactions between hearing mothers and deaf children. Maternal stress was also found to be more common in hearing mothers of deaf children than hearing mothers of hearing children (Harris 1982).

While quality of communication between mother and child is known to exert effects in many areas of development, the relationship between communication and maternal dominance is not straightforward. On the basis of research with 41 hearing impaired toddlers and 41 hearing toddlers and their hearing mothers, Lederberg and Mobley (1990) concluded that level of hearing loss did affect the ability of mother and toddler to communicate effectively. However the two groups did not differ on qualitative ratings of dominance or directiveness, or security of attachment to their mother.

Research in the area of language and social interaction between deaf children and their hearing parents has shed light upon many aspects of the developmental environment. From a review of literature describing the linguistic and social interaction of deaf pre-school children and their hearing mothers, Meadow et al (1981) conclude that mother-child interaction is related to the deaf child's communicative competence. In a somewhat circular manner, research on deaf pre-schoolers suggests that communicative competence is related to the amount of time infants spend interacting with their hearing mothers (Greenberg 1980). Other research suggests that some aspects of deaf children's social competence are unrelated to their communicative competence, but are related to the *method* of communication used (Greenberg 1984 cited in Lederberg 1991). A study of 29 deaf 3-5 year olds (Lederberg 1991) concludes that children rated as having a high language ability displayed more pro-social behaviours, although the overall independent evolution of language and social skills was maintained.

As the deaf child reaches school age, the secondary effects of deafness appear to have greater impact (Lederberg 1993). Schlesinger and Meadow (1972) found that in comparison to hearing peers, when interacting with their mothers, deaf 2½-4 year olds were less compliant, less creative, less happy, enjoyed the interaction less, and showed less pride when playing with their mothers. The deaf children's affective and social behaviour was positively correlated with their communication ability.

The issue of communication choice for hearing parents is not straightforward. Many parents also find the use of the visual field of attention a practical problem.

Unsatisfactory and frustrating experiences of communication often ensue, which may lead to a reduction in communication or withdrawal. The problem of divided attention (Wood et al 1986) may decrease the amount of interaction and communication between deaf children and their parents and also cause adults to be less responsive to deaf children's attentional focus (Lederberg 1993).

Early intervention work now promotes the development of a strong common language base within the family with the aim of benefiting the individual emotionally, cognitively and socially and allowing the family to facilitate growth in themselves and their child (e.g. PATHS project, Greenberg, Kusche 1993).

> Early intervention, emphasising parental acceptance, parent-child interaction, and an effective programme of language development is seen as the best preventative mental health measure for reducing the high prevalence of emotional and behavioural problems among deaf children and adults (Stein, Jabaley 1981)

Much of the research reported in this section has concentrated on the experience of the 90% of deaf children born to hearing parents (Densham 1995). Valuable research has compared interaction patterns between deaf and hearing mothers and deaf children. For example, a study by Gregory and Barlow (1989) suggests that in comparison to deaf mothers, hearing mothers have difficulty in structuring interaction, specifically in establishing mutual play and joint activity with deaf infants. Deaf infants attended to their mothers more than those with hearing mothers (94% compared to 75%), and the deaf mothers actions were more likely to be followed by contingent actions of the child (59% compared to 23%), (Gregory, Barlow 1989). Such studies have increasingly included not only the linguistic fluidity between (signing) deaf parents and their deaf children, but also valuable observations about comparisons in social behaviour between the two groups. For example, a study of deaf children with their deaf or hearing mothers found similarities between the social and linguistic interaction styles of deaf-child/deaf-mother dyads and hearing-child/hearing-mother dyads, and more similarities between deaf-infant/hearing-mother dyads using Total Communication than using oral only methods (Meadow et al 1981). Such studies also confirm that deafness itself does not preclude the development of positive mother-child interaction. As research moves

towards recognising the difference in the cultural experience of deaf adults, attention is directed towards recognition of the existence of culturally different patterns of behaviour in families in which both parents and children are deaf.

No single factors stand out in developmental research as being dominant conditions for positive linguistic or cognitive achievement nor social/emotional adjustment. Nevertheless research suggests a delicate interplay between variables such as the initial response to diagnosis and the quality of early linguistic environment which may combine to create longer term effects in deaf children.

1.5 Education

While the foundations of many aspects of later development are established in the pre-school years, education clearly plays a vital role in continuing development and in preparing the child for independence in adult life. The field of education for deaf children has seen enormous changes since its inception. This account does not aim to provide a comprehensive history of deaf education (for a full account see, for example Ladd 1988, Marschark 1993, Lane 1988). However in order to provide an alternative summary of the influences on deaf child development it is pertinent to trace the significant landmarks in deaf education during this century, and highlight research which considers the longer term effects of education on deaf people's health.

One of the most profound influences on the education of deaf children was the International Congress on the Education of the Deaf held in Milan in 1880, in which it was decided that speech was better for deaf children than sign language. Until this time deaf schools in the UK had been teaching in sign language and utilising the skills of deaf adults. The oralist approach to education began to take effect in the 1860s in the UK. The Education Act of 1889 forced Local Education Authorities to take control of deaf education through the teaching of lip-reading and speech. In pursuit of this goal, teachers often forcibly denied deaf children the opportunity to use sign language in schools (section 1.2). This era, significantly, witnessed the fading out of deaf apprentices, rendered redundant through their inability to teach speech, and the widespread increase in

trained (hearing) teachers. Others argue that the primary reason for their removal was that they were thought to be a subversive influence on deaf children (e.g. Ladd 1988).

In virtually all deaf schools and units the oral philosophy dominated until the 1970s and 1980s. Increasing concern at dropping standards, despite the wide spread availability of hearing aids, led to the Lewis report (1968). The research which led to the Lewis report considered the role of finger-spelling, however although the oral philosophy dominated. oralism was often not strictly the practice in schools. Of 45 schools for the deaf, three-quarters used manual communication in some context, though often unsystematic (Kyle, Woll 1985).

Two bodies of research supported the suspicion that oral education practices were not providing the majority of deaf children with adequate access to education. The first was a study by Conrad (1979) which concluded from his study of a cohort of deaf school leavers in 1974-6 that the average reading age of the sample (aged 16, n=573) was 8.5 years, and this figure was lower still for profoundly deaf pupils. Conrad also rated speech intelligibility. The simplest evaluation can be seen in the proportions of children allocated to the five rating descriptions by their own teachers:

Speech Rating	**Percentage of Conrad Cohort (n=573)**
Wholly intelligible	14%
Fairly easy to understand	20%
About half understood	18%
Very hard to understand	25%
Effectively Unintelligible	23%

Table 1.1 Speech Intelligibility in the Conrad Cohort

From the data in Table 1.1 it is clear that there would be little difficulty in holding a conversation with about one third of these children, but it would be extremely difficult to do so with nearly half of them. When audio-recorded utterances were rated by a group of housewives (unknown to the school leavers), the results were much poorer. Similarly, lip-reading skills within this group, on average, were no better than a hearing child with

no practice. A follow-up report by Kyle and Pullen (1984) suggested that as young adults, very little change had taken place in terms of communication skills.

The second study reflected Conrad's findings in young deaf American students. A survey of the results of the National Achievements Tests, carried out by the Office of Demographic Studies at Gallaudet University in 1974 found that the average 20 year old deaf student, brought up with the oral method had a reading ability below 5th grade level, and only 10 percent of the sample read at above eighth grade level (Trybus, Karchmer 1977)

Following evidence that oral education methods were failing the majority of deaf children, approaches were introduced that incorporated sign language. Total Communication (TC), which involve a combination of 'speech, gestures, formal signing, fingerspelling, lip reading, reading and writing' (Densham 1995, p44) was introduced to some schools by the late 1970s. However, it was not until 1984 that the National Executive Council of the British Association of Teachers of the Deaf formerly accepted TC, (but not BSL) as a method of education available in the education of deaf children (Densham 1995).

This period witnessed the beginning of a steady decline in the number of deaf schools, and an increasing number of deaf children in mainstream schools and units. The character of deaf schools changed during this period, with many more deaf children arriving with an additional handicap, and pupils tending to be 'deafer' on average (DES, Warnock 1978).

By the late 1970s and early 1980s important initiatives were being taken to involve deaf people in the delivery of educational services once again (Ladd 1988). By the early 1990s, BSL/English bilingual programmes were being introduced in deaf schools, as a response to research into the status of BSL.

'Sign Bilingualism' (Pickersgill, Gregory 1998) is:

> ...an approach to the education of deaf children in which the language of the Deaf community (British Sign Language) and the language of the hearing community (English) are used. In the case of children from ethnic minority groups it is more appropriate to use the term 'sign multilingualism' in order to recognise the position of home languages other than English (Pickersgill, Gregory 1998, p3)

There was also increasing recognition that in order for deaf children to acquire BSL as a first language, it had to be encouraged not only by native language users, but separately from English. The involvement of deaf language consultants also facilitated the introduction of biculturalism. A BDA statement on education (1996) outlined the need not only for a 'bilingual environment' (BDA, 1996 p7) in which all staff recognise the importance of both languages and both cultures but also the need to provide a Deaf Studies programme taught by appropriate members of the deaf community.

While many changes in educational provision for deaf children have supported a greater awareness of BSL, and of providing the deaf child with a strong first language, the oral/manual controversy within academic spheres, is still raging. Proponents of oralism claim that evidence has accumulated to justify and sustain considerable optimism over the capability of even profoundly deaf children to develop a fluency of spoken language which allows them to 'live comfortably and efficiently in hearing society' (Lynas, Huntington, Tucker 1988). Consequently, the prospects have 'never been better' even for the profoundly deaf child:

> with recent advances - namely the development of technologically sophisticated high powered hearing aids; an improved understanding of the process of language acquisition; more extensive parent guidance services and better educational practice - even very deaf children, that is, those with profound hearing loss can be enabled to produce and understand spoken language' (Lynas et al 1988, p125).

One of the most influential changes within the field of deaf education has been the increased involvement of parents. The 1993 Education Act was accompanied by 'The Code of Practice on the Identification and Assessment of Special Educational Needs' which strengthened the rights of parents to make informed choices about their deaf child's education:

> ...the knowledge, views and experiences of parents are vital. Effective assessment and provision will be secured where there is the greatest possible degree of partnership between parents and their children and schools, LEAs[4] and other agencies (NDCS Statement 1996).

Research into early communication and interaction strategies (section 1.4.5 and 1.4.6) highlights the importance of deaf children's early language acquisition not only in developing interpersonal relationships (particularly within the family), but in psychological and emotional growth. Recent research in America has studied trends in the use of sign systems in the home as a result of changing educational policy. Marschark (1997) reports that in the 1960s, about 90% of hearing parents used only spoken languages with their deaf children, while the remainder used one or more forms of manual communication. With the introduction of ASL in the classroom in the 1990s, over 80% of children with severe or profound hearing loss experience sign language in school, however fewer than half of those who use sign language in school also sign with their families.

Within the field of education, research points to change at policy level, specifically with the introduction of sign bilingual programmes in many areas and the increasing involvement of deaf professionals, however, many aspects of these changes have still to be fully reflected in patterns of communication between parent and child.

1.5.1 Longer term effects of education

Despite many new initiatives within the field of deaf education, many deaf children continue to be mainstreamed without adequate support or without a deaf peer group. Research on the effects of 'mainstreaming' is growing, and is increasingly concerned both with educational and psychological consequences. For example, Hindley, Hill, McGuigan, Kitson (1994) found a higher incidence of psychiatric problems in children and young people within integrated settings against those at Schools for the Deaf.

One major long-term effect of the oral education policy is to deny some deaf children the opportunity to acquire a strong language base with which to access education. While

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[4]Local Education Authorities

some evidence suggests that 'school signing' exists (Kyle, Woll 1985) often propagated by children of deaf families and employed in a somewhat devious manner behind teacher's backs, access to the language in which *education* is delivered is still deprived.

The effects of deprived language are clearly both short term and longer term. One aspect of this is highlighted in Gregory's (1995) study of a group of deaf children and their families, originally interviewed in 1973, and followed up 18 years later. She reports the majority of parents (76%) as describing their main problem with their child to be communication. Even more (89%) saw this also to be the main difficulty from their child's point of view. In her follow up of 75% of the group many years later, just over half the parents in the study still claimed to be concerned about their son's or daughter's communication skills and over half of this group were extremely concerned (Gregory 1995). Ten percent of the sample of young deaf adults were described as having 'limited language skills' and had to be excluded because the deaf interviewer could not communicate adequately with them. Forty-two percent of this group said they felt sorry for themselves and sixty-four percent wanted to change themselves (Gregory 1995 p184). From an analysis of comments, two areas of concern were identified: the development of communication skills and the development of a sense of identity, or self-esteem.

The relationship between poor language/communication skills and mental health has been explored in various ways. For example, a report showed that of 250 residents in the longest established mental health unit for deaf people, at least 18% had no effective means of communication (Denmark 1994). That is, almost one in five of those who have psychiatric symptoms were deemed not to have effective communication. Of those deaf subjects for whom psychiatric data is available, all but the very youngest experienced a predominantly oral education policy. As we have seen, this has often resulted in, particularly linguistic, underachievement.

The effect of having inadequate language skill cannot be underestimated. Language is a vital component of cognitive, emotional, and social development. The mechanisms by which poor language effects later mental health can be described as direct or indirect. In

a direct sense, poor language and the inability to communicate both to oneself and to others may lead to behavioural outcomes ranging from frustration and aggression to compulsive behaviour or withdrawal. Indirectly, the inability to communicate may disrupt the formation of relationships both within the family and beyond. In turn, disrupted socialisation constitutes a key determinant of mental ill health in later life.

1.6 Conclusion

In summary, this chapter has highlighted points at which the experience of deafness produces different developmental pathways to those of hearing children of hearing parents.

Differences have been highlighted at various stages of development, from early attachment and interaction patterns, often effected, for example, by attitudes towards deafness or by disruptions to normal language acquisition. Poor language skills, in turn, affect socialisation which may obscure access to education.

For many deaf people, membership of the deaf community and the use of sign language are important and positive developmental outcomes of deafness.

Chapter 2 will now consider the wider theoretical constructs both of deafness, and of mental health.

Chapter 2 Deafness and Mental Health: Three Perspectives

2.0 Introduction

Deafness has been poorly understood in terms of concepts of minority, community, and culture. Traditionally, the study of deafness has taken place within several different paradigms. Recently, the most common contrasting perspectives have been the medical and the social. Manfredi (1993) suggests that this distinction is consistent with the distinction between deficiency and handicap. The concept of impairment focuses on the absence of hearing, and handicap, on the social roles and places from which an individual is excluded because of the deficiency.

In line with many sociological and anthropological methodologies, an increasing number of studies examine the identity of collective groups of deaf people, rather than examining the individual. From this approach a cultural view of deaf people emerges. Hynes (1988) contrasts what he describes as the clinical/pathological model of the deaf community, which has individual normalisation as its goal, with the cultural model of the deaf community, the latter aiming to 'accommodate' a collective minority perspective.

Other writers have isolated specific factors in the experiences of deaf people which contribute to a framework within which their experiences can be interpreted. For example, the medico-educational model (SIGN 1998) describes medical and educational professionals' attempts to view deaf people as experiencing delays or deviation from a normal state. This view is contrasted with the socio-cultural perspective which accepts as valid, a minority group experience.

The following section will propose three perspectives on deafness and on deafness and mental health: the medical perspective, the social/environmental perspective and the cultural perspective.

2.1 Medical Perspectives on Deafness

Medical perspectives perceive deafness to be primarily an impairment, as a lack of a sense, and as a deviation from the normal state of hearing (e.g. Collier, Longmore, Hodgetts 1995). Deafness is constructed as a problem requiring a cure, remediation, or the provision of aids (Gregory, Hindley 1996).

Hollins (1997) draws a parallel between the drive to 'cure' deafness and the restitution narrative' which typifies Western medical treatment of illness (Frank 1995). The restitution narrative: 'yesterday I was well, today I am ill but tomorrow I will be better', is identified as a feature of medical ideology which is strongly reflected in societal attitudes to disability. The following extract from a medical handbook on clinical specialities, alludes to this with respect to deafness:

> It is essential that deafness is picked up early, so that as much help as possible can be given to restore hearing (Collier, Longmore, Hodgetts 1995, p540).

While deviation is primarily biological, early literature is quite explicit as to the social expression of deviancy. For example, one account of preventative mental health planning considers the need for:

> ...mental hygiene programs such as sex education and preparation for marriage for young deaf persons in school or college...no group is more entitled to counselling in marriage, parenthood and genetics than the deaf (Rainer, Altshuler, Kallmann 1969, p217).

Similarly, a study of 'lesser mental illnesses' in deaf people is based on a series of investigations which included the following:

> ...a study of 51 deaf persons indicted for various offences (Rainer et al 1969 p143) indicated that the largest number, 19, were sex offenders, eight were charged with assault, seven with disorderly conduct, and the rest were booked for burglary and theft, murder, manslaughter, forgery, and dope peddling. Misdemeanour charges involved vagrancy, reckless driving, shoplifting and bookmaking (Vernon cited in Grinker 1971 p15).

Clearly an association is made between deafness, illness and social deviancy. Medical perspectives crucially locate the source of illness and deviancy within the individual (as a

result of deafness) rather than within the environment. Consequently, language deficiency is also 'blamed' on deafness, and so, on the individual (Kropka 1979).

> The basic problem of the prelingually profoundly deaf child is that they cannot acquire speech and language normally (Denmark 1978 p1)

Such beliefs were enhanced by theories of a relationship between hearing and thought processes, which stated that without hearing, language, thought processes and the growth of the mind were hindered. The lack of verbal skills, often equated with the lack of any language, has lead to generalisations about the surprising ability of seemingly languageless deaf people to perform complex cognitive tasks (Vernon 1971).

Where the use of sign language among deaf people is acknowledged, it is discussed as a primitive necessity. Attempts at communication between deaf and hearing people are presented as problematic, and the deaf person is often portrayed not only as the location of the problem but as the *only* person at a disadvantage.

Proponents of the medical model are found predominantly within the professional body which 'services' the deaf community, and consequently they often command enormous power. Lane (1992) highlights the process by which medical professionals 'medicalise the child's deafness into deviance' (Lane 1992 p24). A deaf child born to hearing parents is initially recognised as different. It is only when the child is subsequently presented to various hearing experts that the medical or the 'infirmity model' (Lane 1992) is legitimated, and the child acquires an 'infirm' label. For both parents and professionals, the psychological link between deafness and illness is also exacerbated by the fact that contact between deaf people and professionals is predominantly hospital based, a location associated with illness.

In general, professional activity is concerned with the various means to restore the individual to as normal an existence as possible. For example, the field of deaf education (section 1.5) can be paraphrased as the ongoing obsession with the teaching of speech, with the goal of concealing the deaf child's handicap often using intrusive and at times barbaric methods (Ladd 1988, Lane 1992). Teachers of the deaf over the years have had

as a goal, the acquisition of speech and lip-reading, often at the cost of learning (Conrad 1979). The promotion of oralist teaching methods has a dual advantage. It satisfies parent's often unrealistic wish for a normal child (Harris 1995), who can at least speak if he/she cannot hear, and it also satisfies professional responsibility to 'make normal' if they cannot 'cure' deviance.

In recent years, arguably the most controversial move to 'restore hearing' has been the development of cochlear implants. Cochlear implants are:

> electrically assistive hearing devices that process and deliver an electrically amplified signal directly to the acoustic nerve, unlike the acoustic hearing aids, which amplify sound to the ear (Hindley 1997, p113)

Despite the many ethical dilemmas (Hindley 1997), cochlear implantation is on the increase. One piece of independent research concludes that the benefits offered by implants over conventional hearing aids are at best slight (Allens, Rawlings, Remmington 1993, cited in Hindley 1997), and the cost, great (estimated at £24,000 for an adult, followed by £1000 maintenance costs a year, and for a child £28,000, with annual maintenance costs of £2,500 a year (Hollins 1997, p3)). In addition, implantation surgery has been described as traumatic and invasive (Lane 1992), particularly to young children. Nevertheless, within the medical framework any 'improvement in a deaf child's ability to perceive sound, and so speech, is of benefit to them' (Moog, Geers, 1991, cited in Hindley 1997).

Professionals involved in cochlear implantation programmes, while often genuinely concerned with how they can best patch gaps in ability or experience, often do not explore alternative approaches to rehabilitation. For example, Lane (1992) reports on a meeting between representatives of the deaf community and medical professionals involved in cochlear implantation surgery. When asked why they had not considered the deaf community and ASL as an alternative to implantation, the professional replied that 'we tend to present things from our point of view' (Lane 1992 p24).

In many domains, the medical view is both powerful and dominant, consequently professionals working within the field of 'medicalised' deafness are often accorded high status within society.

2.2 Medical Perspectives on Deafness and Mental Health

Medical perspectives on deafness encompass much of the literature surrounding mental illness among deaf people. Intrinsic links between deafness and deficiency or deviancy, facilitate the interpretation of mental illness as somehow an inevitable consequence of deafness. In some cases, the boundaries between social deviancy and mental illness blur to the extent that 'burglary and theft' are described as 'lesser mental illnesses' (Vernon 1971, p15).

2.2.1 The deaf personality

The existence of a 'deaf personality' has been a focus of clinical and academic dispute for many years (Montgomery 1989). While some of the literature may appear dated, beliefs about a deaf personality have persisted despite increasing evidence that observed traits have a developmental and experiential aetiology rather than a biological one (e.g. Chess, Fernandez 1980, Remvig 1989).

With reference to the deaf child, Lewis (1968) catalogues the traits associated with deafness. The extract below serves to illustrate the extent to which deafness has been thought to subvert normal personality development:

> Deaf children are often described as immature in self-awareness, egocentric, lacking in self-confidence and initiative, with a tendency to be 'rigid' rather than flexible. Emotional immaturity with poor control of their feelings, poor frustration tolerance, and a persistence of 'tantrums' beyond the period found normally in hearing children, are commonly encountered. Their social development is often inferior to that in the hearing child, their play 'more restricted to the level of action'...with role taking more limited and immature. There is a corresponding immaturity sometimes seen in their moral development. They are thought to show more behaviour problems and tend to blame others, while their moral judgements tend to 'have the black-white rigidity characteristics of younger, hearing children (Lewis, cited in Williams 1970 p1).

The deaf adult has similarly been described as impulsive (e.g. Altshuler 1971, Altshuler 1976, Vernon 1978, Goldstein, Litoff, Felman, 1981) and aggressive (e.g. Altshuler 1964, Cooper 1976), tending to lack empathy and insight, egocentric (e.g. Schlesinger, Meadow 1972) and with a low level of conscience (e.g. Altshuler 1964). Deaf people are thought to adapt to adversity by gross coercive dependence, their reactions to tension and anxiety characterised by a kind of primitive riddance through action (Altshuler 1964).

Vernon (in Grinker 1971) notes that within one population of deaf people, isolation, underachievement and suspiciousness were features of the deaf personality (Cooper 1976, Vernon 1978). With no reference in their report to language competence, deaf people are described as being limited to concrete rather than abstract thinking (e.g. Altshuler, Rainer 1969). Rainer, Altshuler and Kallman (1969) similarly identify the 'primitive personality' of the deaf, characterised by immaturity and temper tantrums alternating with friendly behaviour, inexperience, a lack of empathy, and a lack of critical self-awareness.

Clearly, within a medical perspective, deaf people are often pathologised. Explanation for the deaf personality has traditionally leant upon the existence of different psychodynamic deviance resulting from the lack of audition (e.g. Altshuler, Rainer 1969, Altshuler 1971). Clearly while a relationship is proposed between a deaf personality and the lack of hearing, deaf people are labelled intrinsically pathological.

The notion of a deaf personality has been neatly associated with an increased likelihood of mental illness (Cooper 1976). In its most direct form, belief in intrinsic pathology has led to the proposal of the 'deaf mind' or 'surdophrenia' (Basilier 1964). Basilier concludes that:

> Our experiences are that congenital or early acquired deafness may give a certain personality structure - a surdophrenia - and that deaf people with nervous reactions are in need of specialized psychiatric services (Basilier 1964 cited in Gregory, Hartley 1991, p13).

Critics of the notion of a deaf personality within the professional field have offered other interpretations. Notably, Lane (1992) finds great overlap between the often-contradictory adjectives or traits employed by European colonisers to describe the native Africans, and

those used by hearing 'experts' to describe deaf people. In both cases, Lane observes that the more powerful body seeks to justify paternalistic practices (often contravening the wishes of the less powerful). In the case of deaf people, in order to 'restore deaf people to society' (Lane 1992 p37), it is necessary for deaf people to acknowledge their impairment and to want to be hearing.

2.2.2 Assessment of mental health and illness

Many writers have pronounced investigation into constructs such as the deaf personality, essentially flawed. There are several aspects to this criticism which relate to cultural interpretations of deafness.

The first criticism is that the tests employed have been standardised on hearing samples, and the measures based on hearing norms (Mottez 1981 cited in Manfredi 1993). As Lane (1988) concludes, it is inappropriate to administer such tests to deaf subjects who are likely to compare poorly against hearing subjects. While the norms for deaf people and hearing people are different, and are culturally determined, the results and their interpretations are contentious and could be misleading (Lane 1988).

Lane (1992) draws attention to the many aspects of what he describes as the 'audist' model of the 'psychology of the deaf' which draws on fundamentally inappropriate methods of assessment. For example Lane uses the example of the Thematic Apperception Test (TAT), a projective test in which the subject 'projects' the unconscious forces at play in his personality onto each of nineteen black and white picture cards. Each card has an ambiguous figure presented about which the individual must make up a story. Lane claims that with little understanding as to what they are required to do, many deaf subjects will simply describe the story in an attempt to please the tester (Lane 1992). As Lane explains, should a subject understand the procedure fully, meaningful scores for deaf people on such tests are only available if the examiner possesses an in depth understanding of sign language, and is informed about the 'communicative, cultural and social aspects' of the deaf community (Lane 1992, p51).

The second criticism builds the practice of translating test instruments and assessment situations into sign language. The process of linguistic translation removes linguistic and communication barriers and is widely acclaimed to be an important and positive adaptation. For example the use of sign language reduces the risk of misdiagnosing deafness as mental handicap, of missing psychiatric illness altogether or of diagnosing illness where none exists (e.g. Monteiro 1989).

However, assessment whether in sign language or spoken English, in the majority of cases takes place within a hearing cultural frame of reference. As Hindley (1993) states with respect to children:

> there is a generally accepted assumption that cultural differences do not have major influence on the clinical presentation of child psychiatric disorder (Hindley 1993, p1461).

2.2.3 Prevalence of mental illness among deaf people

Many studies have pointed to an increased rate of mental illness among deaf adults (e.g. Checinski 1991) and children (Hindley, Hill, McGuigan, Kitson 1994). Within a medical framework, studies have focused predominantly on outcome measures. Often with little reference to factors within the developmental environment that may be conducive to mental ill health, research has tended to concentrate on outcome, and on identifying illness and eradicating it.

Studies on the epidemiology of mental illness have tended to be of three main types: hospital based surveys, community based (geographically bound) studies and population based studies.

2.2.4 Hospital based surveys

From a study of psychiatric hospital patients, a direct relationship has been proposed between deafness and paranoid psychosis (Cooper, Garside, Kay 1976), or organic psychosis and psychosis with mental deficiency (Altshuler, Rainer 1969). Altshuler reports that manic-depressive illness and psychotic depression are extremely rare

(Altshuler 1964). In a summary of several clinical based investigations of mental illness in deaf patients, for example, Harry (1980) concluded the incidence of schizophrenia to be between 14% and 21% for outpatients and from 20% to 84% for hospitalised patients. Such incidence data is of limited value without at least comparative prevalence data drawn from the hearing hospital population. Surveys that attempt to contextualise findings are, however, still in the minority. For example, Altshuler and Rainer (1969) drew from comparative data in a sample of hearing patients in their study of 230 psychotic deaf patients in New York State mental hospitals during 1958. They found similar rates of schizophrenia among deaf and hearing people.

In Britain, an analysis of the first 170 people referred to a psychiatric unit for the deaf concluded that the fundamental problem of those with prelingual profound deafness was developmental retardation resulting from lack of sensory experience (Denmark 1966). While there is recognition that poor communication in early development plays a significant role in a maladjusted outcome (Denmark 1985), it is deafness itself that is presented as the handicap to 'total development' and deafness itself that leads to maladjustment in the parent/child relationship. Specifically, in one account, the inability to 'act out' verbally and emotional immaturity was considered to be fundamentally responsible for irritability and explosive outbursts of aggressive behaviour (Denmark 1966).

Misdiagnosis has been recognised as constituting a continual problem, thought to be most often based on an inadequate knowledge of deafness and/or sign language (Denmark 1985). Misdiagnosis due to problematic communication skills between the medical professional and the deaf person is likely to have contributed to deaf inpatients staying much longer in psychiatric units than hearing inpatients. In 1966, Denmark reported that the high incidence of deaf people in mental hospitals was, in part, a result of the fact that the average length of stay for deaf people was 20 years 4 months. A study over twenty years later found the length of stay in Belgium to be 21 years on average compared to 148 days for hearing people (Timmermans 1989). Clearly the risk of misdiagnosis casts doubt on the validity of incidence figures.

2.2.5 Community based surveys

Community based studies of mental illness within the deaf community are becoming increasingly common, often justifying the call for an increase in localised psychiatric services. The rate of schizophrenia within a geographically drawn sample of deaf people was found to be two to three times higher than data for the hearing population drawn in the same way (Checinski 1991). An adapted version of the GHQ-30 together with a psychiatric assessment revealed that 40% of deaf people from two London boroughs displayed emotional behaviour which was characteristic of mental illness. Interviews with 102 deaf adults in the Manchester area using the GHQ-12 ratings, concluded that 37% of people had a positive score indicating psychological distress (Ridgeway 1997). A study of a geographically bound deaf population (n=273) in Northern Ireland revealed that 17% had ongoing mental health problems (Coates, McClelland 1993).

This picture is compounded by a low take up of services at every stage of passage to psychiatric health care services (Checinski 1991) and again, by problems in communication between professionals and patients.

2.2.6 Population based surveys

Various studies have attempted to quantify the nature of psychiatric disorder in deaf children, and most prevalence studies have been population based, typically, school based.

For example, a survey of behavioural problems at a state residential school for deaf children (Meadow, Schlessinger 1971) reported that 12% of deaf children were described as emotionally disturbed, (five times the rate for the general school population), and an additional 20% were judged by teachers to be mildly disturbed. This figure was three times the expected rate. Their report focuses on the need to remove the 'unpleasant reality' of children whose behaviour is 'constantly disruptive' and to increase the mental health services to such children. Lane (1992) also comments that examiner often affects such assessment of behaviour, in this case through teacher bias.

Hindley (1994) provides a comprehensive account of studies utilising school based populations and populations grouped by other methods such as similar aetiological factors (e.g. Chess, Fernandez 1980) in order to estimate the prevalence of psychiatric disorder in deaf children. Estimates of psychiatric disorder range from 15.4% to 54% of deaf children (Hindley et al 1994). Hindley's research, based on a study of 93 children attending a deaf school and three partially hearing units in the inner city, finds the rate of disorder in the whole group to be as high as 50.3% (Hindley et al 1994).

2.2.7 Aetiology of mental illness

To recap, within a medical perspective on deafness, investigations have predominantly focused on outcome measures, often favouring explanations which link psychopathology with deafness over explanations which consider environmental factors. Altshuler (1967, 1971) offers an explanation for patterns of psychopathology that is rooted in psychodynamic theory. Locating many traits as related to the activity of the superego, Altshuler suggests that audition is necessary for the internalisation of rage, which in turn would normally lead to depression or obsessional traits and is also necessary for impulse control.

Acknowledging that mental illness in deaf people may be related to biological factors such as brain damage, Vernon and Rothstein (1968) reported that the most common causes of deafness are among the most common causes of mental retardation, brain damage and epilepsy. Thus behaviour noted as being characteristic of mental illness may be due to an interaction between central nervous system damage and deafness (Vernon 1971).

In summary, medical perspectives locate the source of pathology within the deaf individual. Thus, the drive to remediate deafness, in its extreme form, is fuelled by a belief that deafness itself (rather than any environmental factors) typically leads to a deviant deaf personality, and eventually to such illnesses as surdophrenia.

2.3 Social/Environmental Perspectives on Deafness

Social/environmental perspectives on deafness, while acknowledging that the experience of hearing loss leaves deaf people in a different situation from that of hearing people, transfers responsibility to the social world for ensuring that difference does not become deviance, handicap or a social restriction.

Drawing on parallels in theories of disability, a 'social model of disability looks for a collective, social approach as opposed to an individual medicalised approach' (Hollins 1997, p8). Similarly, Higgins (1980) highlights the 'societal reaction approach' to disability and to deafness which states that the key to understanding the physically disabled is not their impairment but the non disableds' reaction to it (Safilios-Rothschild 1970 p115 in Higgins 1980 p146).

Linking with theories of deviant and stigmatised outsiders, such as homosexuals or black people (Goffman 1963), Higgins (1980) suggests that deaf people also occupy outsider status within a hearing world. Supporting the notion of a social/environmental perspective on deafness, Schlessinger (cited in Steinberg 1991) highlights similarities between 'disadvantaged' children and deaf children in their experience of powerlessness as a subordinate group, within mainstream society.

Higgins (1980) perceives deaf people to deal with their status in a similar way to other outsiders. Some deaf people may attempt to shed their identity as outsiders, for example by learning to speak. Other deaf outsiders form communities that are:

> ...partially a response to the unsatisfying interaction which the deaf experience in a hearing world. The community provides a sanctuary from the curiosity, ridicule and awkward communication which the deaf often encounter among the hearing (Higgins 1980, p170)

Within these communities, the characteristics identifying people as outsiders are likely to become of central importance to their identities. In the case of the deaf community, this characteristic has been the use of sign language. The denial of sign language, for

example in the field of education, has resulted in it being both the symbol of stigma and also the platform for the construction of an outsider identity (Harris 1995).

Having considered the social environment into which the deaf child is often born (section 1.4.3, for a brief review see Bruning-de-Bryn 1989), it is possible to identify many aspects of the developmental experience which are beyond the control of the deaf person, that is, which are located in the social world or environment. These include, for example, the pervasive influence of the ideology of motherhood which stigmatises the birth of deaf children (Gregory et al 1995, and see section 1.4.3), or the observation that the quality of early interactions between hearing mothers and their deaf children is influenced by maternal social support (MacTurk, Meadow-Orlans, Sanford-Koester, Spencer 1993, and see section 1.4.6).

While social/environmental perspectives on deafness often consider dynamics at a societal level, the research referred to above considers the social world to consist of all that originates outside the individual, but impacts on the individual. It would be over ambitious to attempt to catalogue all the factors that have an impact on the experience of deafness. For the purpose of this study, the social/environmental perspective will be focused on such domains as education, family and language.

The social/environmental model shares some theoretical ground with environmentalist theories, such as the development-ecological theory formulated by Bronfenbrenner (Bronfenbrenner 1979) which perceives the individual to be the central focal point of various environmental forces that act both to create and to sustain the individual.

While a social perspective claims to explain the social roots of stress (e.g. Ronayne, Wynne 1985) or of oppression, it also provides a framework for alternative interpretations of more negative outcome measures. That is, traits recognised as occurring with deafness are seen to occur as a result of a social response to deafness.

For example, deaf people are thought to display poor impulse control. While children with acquired hearing loss are found to be at greater risk of developing poor impulse

control, due to factors relating to the aetiology of deafness, those with hereditary deafness, are not (Hindley 1997). A social perspective on deafness rejects the 'audition hypothesis' proposed by Altshuler (1971) to account for observations of weak impulse control in deaf children and adolescents. Harris (in Liben 1978) reviews a body of literature that includes comparisons between the performance of deaf children with hearing parents and those with deaf parents. Harris concludes that good communication within a loving caring parent-child relationship is a good determinant of the acquisition of impulse control, and that the absence of this quality produces poor outcomes.

In a similar way, studies of self-esteem in deaf people show that the degree of self-esteem is positively correlated to the (hearing) parent's communication patterns. In one study, deaf children of deaf parents were found to have higher rates of self-esteem (Meadow 1986). Deselle (1994) demonstrates that the children of parents who used Total Communication have higher self-esteem scores than children of parents who communicate orally. Similarly, self-esteem has been positively correlated with parental expectation (Guterman 1983). In turn, psychological problems are correlated with low self-esteem rather than with any other sociological factors (Austen 1992).

2.4 Social/Environmental Perspectives on Deafness and Mental Health

Within a social perspective, many factors are thought to contribute to a higher rate of mental ill health in deaf adults and children. The main body of literature concerns the socialisation experience.

2.4.1 The developmental environment

To the deaf child, the first encounter with the social world is through the 'family'. As we have seen in Chapter 1, various authors have found correlations between aspects of the early developmental environment, such as the family's reaction to deafness, and later outcomes, for example, in psychosocial development (Manfredi cited in Marschark, Clark 1993, and see section 1.4.3).

The process of adjustment, which begins in the early years, is undoubtedly disturbed by the lack of communication (Gregory et al 1995). Deprivation in language makes it extremely difficult to progress through the various stages of personality development, for example, Greenberg concludes that children who are denied access to adequate communication are likely to learn few and mostly primitive coping strategies from their parents (Greenberg 1983).

In a study of "maladjusted" *(sic)* deaf children, Williams (1970) claims that maladjustment and deafness are not intrinsically linked; however, the inability to communicate is an additional stress on the constellation of environmental and biological factors which lead to behaviour disorders in children.

Clearly, social and environmental forces continue to have an impact beyond early development. Hindley (1997), in a study of the rate of psychiatric illness in deaf children and adolescents, developed screening instruments which were used with deaf children attending both deaf schools and hearing impaired units (HIU). The estimated prevalence across the sample was in the range 43 - 50.3%. In investigating aetiology, Hindley concluded that a number of factors directly unrelated to deafness were associated with psychiatric disorder. While 'social deprivation', 'degree of deafness' and 'communication ability' (as rated by teachers) were not significantly associated with psychiatric disorder, 'family', 'friends', 'self image' and 'school' were. There were significant differences between the HIU and deaf school groups on the 'self-image' and 'school' subscales.

2.4.2 Deconstructing the deaf personality

There are numerous factors which contribute to the social world of the deaf person, particularly during the developmental period. Many of these factors have been discussed in Chapter 1. Within the field of mental health, it has been more difficult to isolate separate factors and locate a direct effect on psychiatric morbidity. However, research increasingly questions medical model assumptions that state *intrinsic* links between deafness and maladjustment.

Proponents of a social/environmental perspective have notably deconstructed aspects of the deaf personality. Greenberg and Kusché (1993) prefer to interpret indications of particular traits as a result of developmental delay or experiential deficit. For example, impulsivity, a phenomenon in many hearing children is usually resolved as the child begins to mediate, verbally and symbolically, their experience. Deaf children in a less than optimal communicative environment are not as well equipped to undertake this transition and are more likely to remain impulsive.

2.4.5 Approaches to treatment

A social perspective on deafness places, at the forefront, intervention work that addresses the high incidence of emotional and behavioural problems in deaf children (e.g. Stein, Jabeley 1981). In recent years, intervention work has been directed at both the family level and at an individual level.

Early intervention, emphasising parental acceptance, parent-child interaction and an effective programme of language development is seen as the best preventative mental health measure for reducing the high prevalence of mental illness among deaf children and adults (Stein, Jabeley 1981). Preliminary work on one intervention project in Vancouver revealed patterns of communication which were developmentally more mature, lower stress and a higher quality of interaction in families who had received intervention (Greenberg 1983).

Social perspectives on deafness increasingly promote the idea that the family can be instrumental in creating and sustaining a protective and healthy developmental environment for the deaf child, ultimately safeguarding later mental health (Bond 1991). For example, in a study of 120 prelingually deaf children, Freeman et al (1975) conclude that while certain aspects of raising a deaf child may be problematic, deaf children (including those with additional disability) do not present psychiatric problems in the majority of cases. In turn, Koester and Meadow-Orlans (1990) identify the single most important coping resource or 'buffer' (Hindley 1997) for mothers of deaf children to be

their social support network or perceptions of social support (Quittner, Glueckauf, Jackson 1990).

Intervention programs such as PATHS[5] (Greenberg, Kusché 1993) focus on the social and cognitive skills necessary for normal social and personality development. The rationale behind PATHS is that healthy coping and adaptation in children and adults depends on propitious links between language, thought emotion and action. The PATHS project incorporates the observation that children between three and seven years benefit enormously from being able to associate their behaviour with symbolic representations, via internalised language.

A social/environmental perspective on deafness directs attention primarily towards removing language barriers between deaf and hearing people. A recent survey of general practitioners revealed, as one might expect, that miscommunication often occurs between general practitioners and deaf patients. More significantly, doctors were satisfied that fairly primitive attempts at overcoming communication barriers would level the playing field to allow access to primary health care (Naish, Clarke 1998). Clearly this approach to the detection of mental illness among deaf clients may generate misleading information.

The social/environmental perspective proposes that mental illness, far from being intrinsically linked to deafness, results from the fact that the majority of deaf children are born into a social and developmental environment which is not attuned to their needs. As a result they are more likely to experience delays or disruptions in many developmental domains, e.g. language acquisition, socialisation, and personality development, and mental illness is one likely outcome of this. Initiatives within the field of mental health aim to smooth out disruptions to the developmental environment, as well as to remove language barriers to the assessment of mental health problems and the delivery of mental health services.

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[5]Promoting Alternative Thinking Strategies.

2.5 Cultural Perspectives on Deafness

Cultural perspectives on deafness have as a core principle, the belief that deafness is an ethnic phenomenon (Johnson, Erting 1982). The experience of deafness places an individual in a position to affiliate, with other deaf people, in a linguistic and cultural sense. Deaf people come together *because* of shared language, experience and beliefs. As with other minority groups, the deaf community has it's own set of attitudes and a way of behaving (Johnson, Erting 1982) and its own worldview (section 1.1.2), so in this sense, affiliation is a cultural phenomenon.

As Moorhead states, from his research into the meanings of deafness, deaf people do not accept the limitations imposed on them by meanings of their experience created by others (Moorhead 1995). As a result, deaf minority culture emerges, in part, in resistance to dominant cultural ideology. Aspects of the cultural experience of deafness may be described as 'celebratory', often centering on shared language (Padden, Humphries, 1988).

To cultural insiders the importance of sign language is indisputable (section 1.2), described by one author as pivotal in the 'deaf construction of deafness' (Harris 1995). In a review of literature supporting the idea that deaf people constitute a linguistic and socio-cultural minority group, Johnson and Erting (1982) see sign language as constituting a means of identification between members:

> The role of self-recognition and recognition by others is critical to the formation and maintenance of ethnic groups, and highlights the role of ASL in maintaining the boundary between the Deaf group and outsiders (Johnson, Erting 1982, p4).

However, motivation to join the deaf cultural community is deeper than a simple desire to be around those who share the same language. Motivation for membership is described as a matter of necessity, as a need to associate with those who have a similar *worldview*.

It is within a cultural model of deafness that the notion of insiders and outsiders is located. Higgins (1980) describes the deaf community as fulfilling a sense of wholeness between those otherwise treated as social outsiders, consequently:

> Because life in the community is fulfilling, there is rarely ever any overwhelming desire to hear (Higgins 1980 p171)

As Lane (1992) says, hearing people are necessarily outsiders. Of particular relevance is the belief that an understanding of cultural deafness to hearing people necessitates changing one's frame of reference:

> True representations of another culture cannot be had without a change in frame of reference, which requires, at least, understanding and empathy. It is naïve to imagine otherwise, and it is self-defeating (Lane 1992 p12)

While deaf people themselves may have identified with a cultural status for many years, such recognition is only a relatively recent phenomenon in the services provided to deaf people. For example in the field of education (section 1.5), the promotion of bilingual/bicultural teaching methods within deaf schools reflects a need to recognise the separate and different experience of many deaf people, and increasingly employs deaf adults as cultural role models (Gregory, Hindley 1996, Young 1995, Kyle, Sutherland 1993):

> It is the community where the communication and the language fit him [*sic*] the deaf child perfectly, it is the community where he is not considered someone who has to learn everything from parents, teachers and speech therapists. The deaf community at a school is a natural group phenomenon that provides correction for the often frustrating experiences in the hearing world (Woodward 1982, cited in Loncke 1989, p30)

Within the domain of the family, Henderson and Hendershott (1991) sow the seeds of a cultural perspective into a family systems approach to raising a deaf child. They suggest that the family can be liberated from the deviancy label attached to having a disabled child, by accepting that the family culture becomes both deaf and hearing. In turn the doors are opened to a bilingual/bicultural developmental environment in which sign language as well as spoken language is prominent.

To summarise, a cultural perspective emphasises the growth of community life from shared experience and through the expression of a shared language. The use of sign

language is paramount, and is perceived both by insiders and increasingly outsiders as one of the central features of the deaf cultural minority community.

2.6 Cultural Perspective on Deafness and Mental Health

Cultural perspectives on mental health and deafness rest on the belief that as a cultural community, a collective perception of mental health exists. This perception may depart significantly from dominant and particularly medical models of mental health.

The field of cross-cultural psychiatry has been expanding considerably in recent years. Increased recognition of multiculturalism within society has led to research in to the presentation and interpretation of various behaviours within different ethnic groups. For example, Littlewood and Lipsedge (1989) explore the existence of psychosis in a young Rastafarian man whose religious and cultural beliefs and practices dramatically influenced the presentation of symptoms.

The expression of (mental) illness behaviour among deaf people is known to reflect cultural and linguistic mores. For example, research has been undertaken into the presentation of thought disorder among deaf people with schizophrenia (Thacker 1991). The form of disorder related closely to the social and linguistic experience of cultural deafness. In addition, the expression of disorder was often through sign language, and it was from this cultural and linguistic baseline that deviation took place.

Within the mental health field, hearing professionals have demonstrated only limited appreciation of a deaf cultural perspective on mental health. The deaf community is often thought to be a *resource* within the mental health field. For example in an address to the European Congress on Mental Health and Deafness, Andersson (1989) makes the following suggestion:

> ...deaf mental patients should be put together in a separate ward and deaf clubs should be enlisted to provide supporting services to mental health professionals and deaf clients...since communication is vital for mental health, deaf people must, of course, have a separate place where they can communicate freely and enjoy sharing their experiences (Andersson 1989 p19).

However, this attitude, whilst acknowledging the important resource and support offered by other culturally deaf people, is more appropriately aligned with medical perspectives in assuming the hearing professional to be a central locus of control of cultural dynamics.

Lane's (1988) description of acculturation among hearing professionals is particularly pertinent. In a study of self-concept in deaf children, Cates (1991) interprets differences in teacher and (deaf) student rating scores within Lane's model of acculturation:

> Hearing teachers of deaf students, although to some extent immersed in deaf culture, may nevertheless be sufficiently socialised in the hearing environment so as to fail to grasp the nuances of expression of self-concept among their deaf students (Cates 1991 p358).

A small number of studies are beginning to explore the need both for linguistic and cultural knowledge and understanding within the field of deafness and mental health (e.g. McEntee 1993). In an examination of the affects of the ethnic identity of the interviewer within the diagnostic process, Hindley (1993) concludes that the cultural capital of the interviewer significantly effects the diagnostic process. Silo (1991) categorically states that hearing people, regardless of their level of training or experience cannot function well as mental health workers with deaf children and adults because of their preconceived ideas about what constitutes normal. Silo concludes:

> Deaf professionals or lay people are reality...our achievements are not something based on 'I heard...' or 'I read...'. We know the path, we know the struggle...we want to see the deaf children of today become all round deaf adults of tomorrow...our goals are healthier, not restricted, because they are grounded in reality. It is not based on airy fairy stories, but based on blood, sweat and tears of our experience (Silo 1991, p26).

Concerns surrounding cultural misinterpretation have been reinforced by suggestions that deaf people mistrust hearing professionals who do not know sign language and do not understand the cross-cultural implications inherent in deafness (Farrugia 1988). This research adds another dimension to existing findings into the low take up of mental health services within the deaf community (Checinski 1991). Steinberg (1991) estimates that 90% of the deaf population's mental health needs remain unserved. In recognition of this situation, in America, legislation under the Americans with Disability Act asserts deaf

people's rights not only to interpreters but to professionals with appropriate experience and understanding (Pollard 1994).

2.6.2 The involvement of deaf adults in prevention, assessment and treatment

Early intervention projects in particular are increasingly utilising deaf adults as role models to children and to their hearing parents. As Greenberg (1983) states, the involvement of deaf adults in intervention programmes allows hearing parents to develop their attitudes towards handicaps, develop realistic perceptions of deaf people while at the same time providing their children with deaf adult role models. Similarly the Deaf Children at Home Project in Bristol (Kyle, Sutherland 1993) provides hearing parents of deaf pre-school children with the opportunity to confront their own cultural identity with the help of deaf adults, in the context of their parenting a deaf child.

Deaf people's involvement in the provision of mental health services is increasing (Young, Ackerman, Kyle, 1998). However, very often the literature focuses on the justification for such involvement (e.g. Shrine, Draper, 1990), diverting from an investigation of cultural notions of health and how they might actually be reconstructed by deaf people. In a study which explores deaf and hearing people's working relationships within organisations such as psychiatric units (Young, Ackerman, Kyle, 1998), two crucial components of change merge. The first appears to be the necessary *deconstruction* of an organisation in order to allow deaf people's participation at an equal level. The second was the need to acknowledge different cultural meanings to events that took place within the organisation.

Deaf people have rarely been involved in defining their own cultural interpretation of health. Deaf professionals, while working within a profession which is dominated by hearing professionals and surdocentric practice, appear limited in their capacity to explore deaf cultural perceptions of mental health and illness.

A cultural perspective on deafness and mental health provides the framework for a very different perception of health. The following section considers one model that provides a

highly suitable framework within which to develop a model of the way deaf people perceive mental health. In seeking the best way to contextualise a deaf perception of mental health, wellness theory has developed.

2.7 Wellness Theory

Within the field of mental illness there is a tendency to focus on symptoms (Hunt, McKenna 1992), and psychopathology rather than subjective perceptions of mental well-being. Consequently once illness has been identified there is increasing concern to understand the process by which something went wrong and how best to respond with treatment. Wellness theory asks what goes *right* in psychological development and adjustment, and seeks to identify the factors that are perceived by the individual to create such an outcome.

A state of wellness can be thought to occupy the extreme point of a continuum, the other end of which can be found pathology. However wellness, as Cowen (1994) suggests, is more than the simple absence of disease, rather it is defined by the presence of positive characteristics of adjustment.

Wellness can be defined in terms of a 'broad range of positive outcomes, including physical and psychological health' (Lightsey 1996). It can also be seen as:

> a state of harmony, energy, positive productivity, and well-being in an individual's mind, body, emotions and spirit. The state of wellness also extends to the relationships between the individual and his or her family and other interpersonal connections as well as between the person and his or her physical environment, community, and larger society...wellness does not preclude having a disability or experiencing positive stress (Jones, Kilpatrick 1996 p259).

As wellness theory embraces an holistic view of health, wellness, in turn, involves:

> attention to the biological, psychological and spiritual aspects of person-in-environment functioning constitutes an essential part of the wellness process (Jones, Kilpatrick 1996 p259).

Research has attempted to pinpoint the essential components of wellness. In related work on well-being, Ryff and Keyes (1995), from a telephone survey of 1,108 American adults

suggest a model of well-being which comprised six components; autonomy, environmental mastery, personal growth, positive relations with others, purpose in life. and self acceptance. Lightsey (1996) in a review of empirically based research explores the role of four personality traits (positive thoughts, hardiness, generalised self-efficacy and optimism) and psychological resources in human well-being. Lightsey (1996) arrives at several conclusions, for example that optimism is strongly associated with physical and psychological health.

2.7.1 The role of wellness theory in contextualising deafness and mental health

Wellness theory is particularly germane to the consideration of mental health and how it may be interpreted within the deaf community. Four aspects of this suitability will be examined; focus on indicators of adjustment, independence from dominant ideologies of health, the promotion of culturally agreed indicators of wellness in addition to individual expressions of wellness and finally a concern for the process of wellness. Each will be examined in turn.

2.7.1.1 Focusing on indicators of adjustment

Wellness theory focuses on positive indicators of adjustment and coping. Clearly many perspectives on deafness and mental health focus almost entirely on the existence and impact either of pathology within the individual or within the environment. Few approaches incorporate the expression and interpretation of signs of positive adjustment.

2.7.1.2 Independence from dominant ideologies of health

Wellness theory is independent from traditional approaches (i.e. beliefs grounded in a medical model of deafness and mental health, or traditional notions of deafness and disability). Earlier sections of this chapter (sections 2.2 and 2.4) have provided an account of the limitations of such models in understanding deafness and mental health.

2.7.1.3 The promotion of culturally agreed indicators in addition to individual expressions of wellness

Wellness theory can be explored on both an individual level and on a collective, community basis.

On an individual level, definitions of wellness rely on subjective experience, individual perceptions and the belief that interpretations constitute a legitimate construction. Of particular relevance to this study, wellness may also be conceptualised as a culturally agreed phenomenon. Chapter 1 introduced the notion of the deaf community as an active linguistic and cultural minority community. This idea was further explored in section 2.5 and 2.6, which examined cultural perspectives both to deafness and to deafness and mental health.

Cultural diversity exists in the expression and interpretation of wellness. Many of the principles of cross-cultural psychiatry provide an appropriate conceptual link to notions of cultural variation within wellness theory.

Reflecting an increasingly ethnically diverse society, the field of mental health has slowly begun to review traditional approaches to diagnosis and treatment based on 'ethnocentric' normative criteria. Traditional beliefs have seen normalcy and deviance through the 'cultural lens' of the dominant group in society (Caismir, Morrison 1993, p.548, Currer 1986). Using the specific example of psychotherapeutic practice, Lloyd and Bhugra (1993) draw attention to the two extremes existing within the Western cultural practice of psychotherapy. At one end of a continuum lies the universalist position which supposes that Western psychotherapies are of value in any cross-cultural setting because individuals share more similarities than differences in terms of individual development, social rules and tasks. At the other extreme is the cultural relativist notion that each culture is unique and for this reason cannot be considered under the same theory.

Wellness theory draws on elements of this continuum. Beliefs about wellness originate within constructivist theory, which promotes different ways of thinking about and talking about reality. As Jones and Kilpatrick (1996) outline:

> Constructivism is predicated on the premise that multiple perceptions of reality cluster around a single event or situation and that all of these perceptions have validity (Jones, Kilpatrick 1996 p260).

Together with multiple perceptions of reality, built into any definition of wellness are overt and covert expressions of values (Cowen 1994). Clearly, values differ both across cultures and within cultures and indeed often differ between individuals.

Wellness theory can be read at two levels with respect to cultural diversity. At the first level, commonalties have been traced in outcome characteristics of wellness. Cowen (1994) suggests that these fall into two or possibly three groups. Firstly, behavioural markers such as eating, sleeping, working well, having appropriate interpersonal relationships and mastering age and ability appropriate tasks constitute features many people would value positively. Secondly, Cowen (1994) sites psychological markers such as having a sense of belonging and purpose, control over one's fate, and satisfaction with oneself and one's existence. Cowen (1994) also cites physiological markers as potential baseline indicators of wellness.

At a second level of analysis, the process and nature of such characteristics can be determined by cultural consensus. One review of the expanding body of literature in the field of subjective well-being (Lightsey 1996) concludes that while aspects of subjective well-being are common across cultures, the schemata with which such experiences are defined as positive and adaptive, vary in content across cultures.

2.7.1.3 The wellness process

Interest in identifying the components of wellness has been balanced by exploration into the wellness process, that is, the nature and dynamics of the journey towards a state of well-being.

Several factors have been identified as disruptive in the process of attaining wellness. For example, wellness is described as resulting from a congruent fit between the intrapersonal body systems, personal relationships with other human beings and the comprehensive environment in which the individual functions (Jones, Kilpatrick 1996). Consequently,

disruptions in any of these areas can jeopardise the attainment of wellness (Jones, Kilpatrick 1996).

Section 1.3 described the process by which many deaf people make a transition from the hearing culture of their parents to cultural affiliation with the deaf community. This phenomenon highlights the need to consider 'process' within a study of wellness. For many deaf people, adjustment and change are defining features of the experience of deafness. For deaf people, the pathway to wellness can be seen to be unprotected and dangerous, unlike hearing people whose development and developmental environment is comparatively stable. It would be pertinent to propose that such features of experience also have significant impact on an experience of wellness.

Cowen (1994) provides a useful framework for this in the identification of five 'pathways' to wellness. Each pathway maintains salience at different ages and for different groups and life conditions. The notion of pathways also facilitates potential change during the lifetime. The five pathways are:

1) Forming wholesome early attachments.

2) The development of age and ability appropriate competencies.

3) Engineering settings that promote adaptive outcomes.

4) Fostering empowerment.

5) Acquiring skills needed to cope effectively with life stressors.

Cowen (1994) describes the first two stages as imperative in the development of a sense of efficacy and with this, ultimately a phenomenological sense of empowerment. In turn, this progression depends upon the infant being developmentally nourished by home and latterly by school. Chapter 1 considered the invaluable properties of the developmental environment for the deaf child. Given the obstacles in place along the pathways to

wellness, it is important to note the crucial characteristics and meanings attributed to the pathways, by deaf people.

The third, fourth and fifth pathways to wellness are influenced by the quality of an individual's community. Throughout development and socialisation, the individual meets a greater number of increasingly complex systems such as employment or justice (Cowen 1994). The pursuit of wellness necessitates the identification and negotiation of such systems in a way that will best benefit the individual.

Cowen's fifth pathway to wellness concerns the ability to cope effectively with stress, either in a reactive capacity or more insidiously. Cowen (1994) highlights a substantial body of literature that draws on experiences of disempowerment for example through ethnic-bias, as contributing to the most damaging assault on the achievement of wellness.

Again, highly pertinent to the study of deaf people and mental health, wellness theory also assumes that 'continuous, multilevel, reciprocal communication occurs between people and their contextual environments' (Jones, Kilpatrick 1996 p259). As we have witnessed throughout Chapters 1 and 2 communication is a vital ingredient to positive adjustment, and clearly pathways to wellness are highly dependent on the ability to communicate and to negotiate the 'contextual environment'.

Wellness theory offers a highly suitable framework within which to consider deafness and mental health. While Cowen's model of wellness draws from dominant cultural constructions, the principles of the model may be applied in culturally diverse situations. Cultural perspectives on deafness propose that within cultural groups, a worldview exists based on life experiences, which is distinct from the worldview of the dominant culture. This worldview contains collective beliefs as to what constitutes normal and abnormal behaviour, wellness and illness. Communities maintain a homeostatic state on the basis that wellness behaviour is identified as the normal state, and deviations from this state represent illness. Within the deaf community, wellness theory offers an interpretative framework for what is essentially a *different* perception of mental health.

2.8 Summary

This chapter has introduced three perspectives on deafness and mental health; a medical perspective, a social/environmental perspective and finally a cultural perspective. Each perspective has been evaluated in terms of its application to an understanding of the experience of mental health within the deaf community.

While a cultural perspective offers the most appropriate framework within which to site this study of mental health, it is necessary to look at related fields of research to find a model within which to interpret finding. Wellness theory offers such a framework.

The following chapter introduces the methodological framework for the study.

Chapter 3 Methodology

3.1 Research Questions

The incidence of psychiatric disorder is higher in the deaf community than in the hearing population (Checinski 1991). In addition, patterns of distribution are significantly different from the hearing population. Research has examined many aspects of the epidemiology and aetiology of mental illness among deaf people. While yielding important information, both epidemiological and aetiological studies have been based on a pathologising of deafness (section 2.2). This framework makes the exploration of positive and differing cultural notions of health and illness, difficult. In addition, studies with deaf people have not adequately considered the evolution of a state of wellness or conversely of ill health.

In addressing these limitations, the following four studies encompass four main research questions:

> What is the degree of psychiatric morbidity in one population of deaf people, as reflected in referral rates to specialist units?
>
> What are the indications of undetected mental health problems in the same population?
>
> What characterises experiences of wellness and illness for members of the deaf community?
>
> How are we to understand deaf people's mental health and adjustment?

The following section will first consider Studies 1 and 2.1, which constituted the quantitative component of the research. The qualitative component will be introduced in section 3.11.

Study 1 constituted a quantitative analysis of referral patterns for psychiatric illness within the Conrad Cohort. The second study was in two parts; Study 2.1 examined psychiatric morbidity within a sub-sample of the Conrad Cohort, by means of subjective health assessment scales. Study 2.2 examined, through qualitative interview, the

conceptual approach to and experience of wellness within the same sub-sample of the Conrad Cohort.

3.2 Study 1 (Feb. - May 1995)

3.3 Theoretical Background to Research Design

Evidence of the rate of psychiatric morbidity and psychological maladjustment in deaf people have come mainly from three types of study.

3.3.1 Hospital Based Studies

Hospital based studies offer the opportunity to review patterns of presenting disorder, and to analyse processes and practices in mental health service delivery.
Surveys of this nature draw upon large populations of deaf people in predominantly health care settings. Admission to such hospitals may be due to psychiatric illness (e.g. Denmark 1985) or the need for other medical services, for example services offered by an Ear Nose and Throat Department (Mahapatra 1974).

While such studies are successful in establishing outcome measures, it is within a medical model of deafness that the majority of such studies take place, which, in turn, is not conducive to a broad understanding of illness.

3.3.2 Community Based Studies

Research has also studied people living in geographically bound areas. For example, Rainer (1968) conducted a study of mental health problems within a sample of approximately 12,000 'literate and totally deaf' *[sic]* subjects, collected over a number of years from within the State of New York. More recently Checinski (1991) examined the level of psychiatric disorder in deaf adults in two London boroughs, exposing an inflated rate of mental illness.

While allowing for a regional assessment of epidemiology and service provision, studies of this nature display certain limitations, for example, in not producing generalisable

findings. Community based studies, comprising a naturally wide age range are also unable to provide a thorough investigation of causal factors, which have different impact on people at different ages and in different social and political climates.

Studies of this nature are also limited in their ability to generalise to geographically diverse communities.

3.3.3 Longitudinal Population-Based Studies

Longitudinal population based studies offer the opportunity to chart the pathways of mental illness. A 'longitudinal' project requires an assessment of subjects at a minimum of two points in the lifespan. Within such a research design, the points of measurement are relatively wide spaced, thus accommodating for the 'sleeper effect', in which the effect of an antecedent factor does not show itself until a later period of life (Mednick, Baert 1981, p15).

The aims of Study 1 were not 'experimental-manipulative' (Mednick, Baert 1981), that is the intention was not to assess the impact of any one stimuli. Rather the objective was to fulfil the criteria for 'correlative and non-interventionist' research, in which 'early characteristics or experiences are noted and correlated with outcomes at later stages of development' (Mednick, Baert 1981, p13).

The following section is based on comprehensive research by Mednick, and Baert (1981). It outlines the benefits and drawbacks of using a cohort population for longitudinal research.

Benefits of Longitudinal Cohort Studies:

1) *Representative*. There is a generalisability of findings.

2) *Charts incidence, prevalence and change*. Such studies allow for the development of incidence and prevalence rates for a range of variables, offering an opportunity to assess the impact of change, for example, social, educational, or economic.

3) *Multi-purpose*. A large amount of data can be stored on one population, providing the opportunity to examine the interaction of disparate variables in a relatively straightforward way.

Considerations

1) *Obsolescence*. Measures and theories that seem important at the inception of a project, may seem dated and misdirected 20 years later (Mednick, Baert 1981).

2) *Interpretation of findings*. Conclusions are often made in an absolute manner, rather than respecting the 'sleeper effect'.

3) *Population flux*. Natural population shifts may occur rendering the population unrepresentative.

4) *Cost and administration*. Longitudinal studies commonly incur large costs, not only in the initial study outlay, but also in the (often hidden) expense of tracing subjects.

In Britain several birth cohort studies are currently underway. For example the National Child Development Study, established in 1958, collected data on 17,000 babies born in Britain in one week. It focused primarily on social and obstetric factors. Since its inception there have been three subsequent comprehensive follow-ups of this cohort (Fogelman, Wedge 1981). Similarly, a cohort study began in Aberdeen in 1949, focusing primarily on aspects of 'medical sociology' (Baird 1949, cited in Gruenberg, Le Resche 1981). There is, however a distinct dearth of equivalent cohort data for deaf people.

3.4 Sampling Procedures Study 1

For this study, a unique opportunity arose to examine a near total cohort of deaf people. Two longitudinal follow-ups complement an original comprehensive data set on a group of people, to be referred to as the Conrad Cohort (n=573).

To date, only one other longitudinal study has been established with deaf people in Britain. In 1974, 122 families of deaf pre-school children were interviewed (Gregory

1976). A follow-up study of both the parents and the young deaf adults (Gregory, Bishop, Sheldon 1995) elucidates many aspects of the deaf child's developmental process. While of great value, the relatively small size of the study in comparison to population cohort studies imposed certain limitations on the generalisability of findings.

The following section examines why the Conrad Cohort represents a highly suitable opportunity to examine indicators of mental health across a total cohort.

3.4.1 The Conrad Cohort

Between 1974-6, a study was carried out by Conrad, and a team from the Medical Research Council Applied Psychology Unit in Cambridge (Conrad 1979). The aim was to investigate the effects of education on the cognitive and educational achievements of deaf and hearing-impaired school leavers. Their sample was a near complete cohort of school leavers, aged between 15-16½ years (n=573), and receiving special educational help, either in a deaf school or mainstream unit, because of deafness.

Department of Education statistics detailing the numbers of children involved in special education programmes at the time confirmed that Conrad reached between 84-90% of all deaf children in that age group at the time of testing (n=573).

The Conrad Cohort represents a special population within a birth cohort. Although the sample, is relatively small compared to total undefined birth cohorts (e.g. NCDS, n=17,000), there are reasons why the data collected in the initial study (Conrad 1979) and subsequent follow-up (Kyle, Pullen 1984) has particular strengths.

1) The Conrad Cohort has the advantage of being a statistically representative sample, from which generalisations can legitimately be drawn.

2) Being of the same age, much is known about the factors Cohort members have in common, in terms of medical, educational and family experience.

3) At the time of study, the majority of subjects were between 34 and 36 years. As the 'sleeper effect' suggests (Mednick, Baert 1981), mental health problems may remain dormant during adolescence, presenting during adulthood (Drew, King 1995).

3.5 Procedure

The research task was to match those in the Conrad Cohort with those known to each of the Specialist Psychiatric Units for the Deaf. Once a match had been established, information relating both to the nature of mental illness and to the profile of the individual was ascertained. This data included, for example, circumstances of admission and family history as well as references to language and communication skills. While an interview with each person might have provided insight into their individual perceptions of health and illness, in addition to primary financial constraints, both ethical concerns and practical considerations advised caution in undertaking research with individuals known to be suffering from mental illness (e.g. SIGN 1998).

3.6 Analysis

A primary concern in quantitatively analysing psychiatric data is that outcome measures are standardised, thus allowing results to be compared easily to those of other populations. To this end an international diagnostic system was used (section 4.3.2). Procedural details can be found in Chapter 4.

3.7 Study 2.1 and Study 2.2 (Feb. - May 1996)

Outcome measures are valuable in ascertaining rates of psychiatric morbidity, particularly when a mental health diagnosis can be correlated with other longitudinal indicators of achievement and adjustment. A question remains, however, over the extent to which this psychiatric data can be extrapolated either to the whole cohort, or to other deaf people. One particular concern was that the low take-up of psychiatric services, particularly in the deaf community (Checinski 1991) would render even high rates of mental illness a significant underestimate. Financial and time constraints prevented a full-scale follow-up of the Conrad Cohorts, however the issue was addressed in another way.

Indicators of psychiatric morbidity and maladjustment in members of the Conrad Cohort *unknown* to the specialist mental health services for the deaf were explored through a sub-sample follow-up. It was hoped that this would provide an indication of undetected ill health. Study 2 consists of two components, subjective standard health assessment measures (Study 2.1) and qualitative interviews (Study 2.2).

3.8 Standard Measure Health Assessment Scales - Study 2.1

People's perception of personal health, well-being and life situation is often discordant with their *objective* health status (Albrecht 1994), or with professional opinion or levels of performance. For this reason, *subjective* health assessment is critical in the assessment of quality of life, often providing a necessary augmentation to the more rigorous practice of 'scientific' medicine.

The number of questionnaires developed to measure subjective quality of life or health status has increased dramatically over the last few years (Jenkinson, Bardsley, Lawrence 1994). With the increase has come an growing concern that measures are sensitive to changes over time or 'responsiveness' (Ziebland 1994, p42).

In a study of many health status questionnaires, Ziebland (1994) considers four main models of illness within which questions are formulated:

1) *The Functional Model.* Items in these questionnaires distinguish between ability and inability to perform a particular function or activity. For example, the respondent is required to affirm which statements, from a selection are applicable to them, such as:

> "*I'm unable to walk at all.*" (Nottingham Health Profile (NHP) Hunt, McKenna 1985, cited in Ziebland 1994, p48).

When used with deaf people, questionnaires of this nature allow a broad domain of 'effect' to be explored very simply. However, in research which aims to investigate aspects of mental/emotional well-being, studies which focus on functional ability are largely redundant.

Questionnaires explicitly concerned with the degree of functional disability carry an implicit assumption that deafness is a direct cause of ill health. Within this model, deafness becomes the variable under question, rather than, for example, difficulties resultant from barriers in communication.

2) *The Subjective Distress Model.* Questionnaires formulated within the subjective distress model are concerned with the degree of difficulty experienced by the respondent. A qualifying adverb provides a measure of severity of any disability. For example:

> *"Today, do you (or would you) have any physical difficulty at all with cooking?"* (McMaster Health Index Questionnaire (MHIQ), Chambers 1982, cited in Ziebland 1994, p48).

Primarily designed for use with respondents experiencing some degree of physical or emotional difficulties in day to day life, questionnaires of this nature, again, would be inappropriate for Study 2.2 as they assume a link between deafness and difficulty.

3) *The Comparative Model.* Variants of this model include respondents comparing their health either to other people, for example:

> *"I seem to get sick a little easier than other people"* (Short-Form 36 Health Survey Questionnaire (SF-36), Jenkinson 1994, p 18),

or to their usual or former condition, e.g.:

> *"I can work for as long as I usually do"* (Self-rating pain and distress scale (PAD scale), Zung 1983, cited in Ziebland 1994 p49)

This type of questionnaire most suitably addresses the objectives of Study 2. The following section details the questionnaires selected.

3.9 Health Assessment Scales Selected - Study 2.1

The GHQ-30, and the SF-36 detailed below have been standardised on hearing populations. In the absence of a similar questionnaire designed for and standardised on deaf people, the use of these two questionnaire offered an opportunity to investigate the state of mental health within the Cohort against hearing norms.

3.9.1 The General Health Questionnaire (GHQ-30, Goldberg 1978).

> "The GHQ was designed to be a self-administered screening test aimed at detecting psychiatric disorders among respondents in community settings and non-psychiatric clinical settings, such as primary care or among general medical out-patients" (Goldberg, Williams 1988 p1).

The GHQ originated from an extensive interview conducted by Veroff, Feld and Gurin (1962, in Goldberg, Williams 1988), of 542 Americans, thought to be representative of the non-hospitalised general population. It was designed to investigate all aspects of adjustment and 'felt distress'. From 140 items selected, component analysis produced the 60 item General Health Questionnaire or GHQ-60. This has been shortened, and the most commonly used forms of the questionnaire are the GHQ-30 and the GHQ-12.

Test items aim to distinguish psychiatric cases as a class from non-cases as a class, concentrating on the 'grey area' between the two. The questionnaire is sensitive to pure state, that is, how the individual feels at the time of interview, thus transient disorders which may naturally remit without treatment, may be picked up. Unless accompanied by other symptoms justifying diagnosis, it would be unlikely to distinguish longer term disorders or functional psychoses over short term (Goldberg, Williams 1988).

A large body of literature concludes that the GHQ appears to perform well in cross cultural settings and it has been translated into at least 36 different languages (Goldberg and Williams 1988 p58). Other studies cite phrases from the GHQ which are culturally inappropriate (e.g. Currer 1986, Lewis, Araya 1995).

Through a process of translation and re-translation of the GHQ-30, Checinski (1991) created a questionnaire appropriately adapted to fit the needs of the deaf community. The GHQ(DP)-33 is still a 'paper and pen' questionnaire, however both the language and content have been adapted to be understood by deaf people. The GHQ-12 has also been adapted by Ridgeway (1997) for use with deaf people, using a similar process of translation and back translation between English and BSL. At the time of Study 2, plans were underway to develop both a video version of the GHQ and an interactive computer

version (both in BSL). However, none of the adapted versions of the GHQ (for use with deaf people) were either available or accessible at the time of Study 2.2.

In Study 2.1 language barriers were minimised by the respondent being able to choose his or her preferred method of administration, which included administration in BSL.

In order to make a clinical diagnosis, the GHQ should be accompanied by a psychiatric assessment. As Goldberg (1986) warns, the GHQ should not be seen as a screening device, and caution advised before assuming that the proportion of people with high scores reflects the actual prevalence of disorder in a particular population. While is advisable to follow-up the questionnaire with an interview by a qualified psychiatrist, this was thought to be financially impracticable, nevertheless, results from the GHQ-30 alone provide a reliable indicator of mental health.

3.9.2 The Short Form 36 General Health Survey (SF-36).

The SF-36 was one of the products of the (long-form) RAND Corporations Health Insurance Experiment (HIE) and subsequent Medical Outcomes Study (MOS) (Jenkinson 1996). Both studies and subsequent SF-36 were characterised by a decision to collect *patient assessed* outcome measures in addition to traditional clinical measures of health and illness (Jenkinson 1996).

One of the aims in developing the SF-36 was to produce a questionnaire that could be used with general population groups as well as with patient groups.

The instrument uses eight dimensions: physical functioning, role limitations due to physical problems, role limitations due to emotional problems, social functioning, mental health, energy/vitality, pain and general health perception.

3.10 Validity and Reliability

An outcome measure should rate highly in tests of validity and reliability, and score well on measures of internal consistency.

Validity is the extent to which an instrument measures what it was intended and it is achieved by statistically significant correlations in the predicted direction. *Content validity* refers to the ability of individual items to perform discrimination between subjects. With respect to health outcome measures, *criterion validity* is the extent to which scores correspond to a 'gold standard' or external criteria of illness. *Construct validity* is evaluated by hypothesising how a measure should behave, and its subsequent performance in confirming or disconfirming the hypothesis.

Reliability is the extent to which similar measurements on the same person produce similar results in different settings.

Finally *internal consistency* refers to the extent to which items contributing to the same scale correlate well with each other.

3.10.1 GHQ-30

For both the SF-36 and the GHQ-30, the method of construction of the questionnaire ensures content validity (Goldberg, Williams 1988, Jenkinson 1994). Criterion validity has commonly best been assessed through an independent measure of psychiatric state by a trained investigator, using a structured research interview for which the reliability has been established. In seven studies involving GHQ-30 and additional interview measures of morbidity, the median coefficient was 0.59 (Goldberg, Williams 1988), which was less than other forms of the GHQ. This value rises to a coefficient of 0.72, if the reliability of the Clinical Interview scale (0.92) is used in calculations (Goldberg, Williams 1988, p45).

The GHQ-30 has median value for sensitivity of 81%, with 21 of 29 validity studies yielding within 10 per cent of this figure (Goldberg, Williams 1988).

Tests of reliability during the development of the GHQ have been of two types. The first calculates the tests' 'split half' reliability, that is, the score on one half of the questionnaire which is compared with the score on the other. Although there are a limited number of studies which consider measures of reliability, results for five trials of GHQ-30

produce a high alpha[6] coefficient of 0.87 for 'split-half' reliability (Goldberg, Williams 1988).

The second measure is the test, re-test method, in which the test is administered to the same subjects on more than one occasion. In samples drawn from the general population, there is considerable movement between caseness and non-caseness which one could expect to result in lower coefficients. However in tests with general population samples there are still significant outcomes, showing good test re-test reliability scores (Goldberg, Williams 1988).

3.10.2 SF-36

The SF-36, provided strong evidence of internal consistency and validity (Garratt, Ruta, Abdalla, Buckingham, Russell 1993, Jenkinson et al 1993, Brazier, Harper, Jones, O'Cathian, Thomas, Usherwood, Westlake 1992). There was also a high response rate ranging from 72-83% (Garratt et al 1993, Jenkinson et al 1993, Brazier et al 1992).

Validity testing has been carried out in the US and UK and has included an examination of the content, criterion and construct validity of the instrument.

Content validity was found to be acceptable, after the SF-20, its precursor was expanded to become the 36 item SF-36 (Wright 1994). Criterion validity was confirmed in a study by Jenkinson et al (1994). Results both from psychometric and clinical tests for construct validity showed high correlation between the underlying nature of each scale and the degree to which each scale measured that component (Wright 1994).

Internal reliability estimates were found to be highly correlated for general population groups, although there is a reported dearth of evidence for reliability over different time periods (Wright 1994).

There was more than satisfactory evidence that the two standard measures selected were statistically and conceptually appropriate to the planned study.

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[6] Cronbach 1951

3.11 Theoretical Background to the Research Design:Study 2.2, Study 3 and Study 4

Since the early 1980s, 'transcultural psychiatry' (Littlewood, Lipsedge 1989) has emerged as a response to more fundamental questions relating to the psychiatric treatment of people from minority communities. The concept of cultural perspective within psychiatry is now considered crucial to the understanding of mental health and illness. Despite being identified as a linguistic and cultural minority group, the *cultural* construction of health within the deaf community remains virtually unexplored.

Research has predominantly been quantitative, documenting aspects of the epidemiology of mental illness. It has primarily been undertaken through surveys that have been predominantly hospital-based (3.3.1), community based (section 3.3.2) or population based studies (3.3.3). Such outcome measures are of value and endorse the findings of Studies 1 and Study 2.1. However the recognition of cultural interpretations of health serves to highlight a gap in our understanding of mental health.

Standard measure assessment instruments of *subjective* well-being and quality of life are used increasingly in research. Although linguistic adaptations have been made to some standard measure assessments of mental health, for example to the General Health Questionnaire (now GHQDP-33, Checinski 1991), assessments are based on deviation from hearing norms. Other questionnaires designed specifically for deaf people focus on other aspects of personality, for example the Attitude and Identity Questionnaire (Ridgeway 1997). Such measures have value but have yet to be applied to the perception of mental ill health.

The objectives of Study 2.2, Study 3 and Study 4, which were to investigate beliefs about wellness rather than performance, necessitated the selection of a qualitative approach. Philosophical roots of qualitative methods emphasise the importance of understanding the *meanings* of human behaviour and the socio-cultural context of social interaction. This necessitates the researcher developing an understanding of subjective experience and the connections between personal perceptions and behaviour. The qualitative perspective...

> ...in no way suggests that the researcher lacks ability to be scientific - it, on the contrary suggests it is crucial for validity - and consequently for reliability, to try and picture the empirical social world, as it actually exists to those under investigation, rather than how the researcher imagines it to be (Filstead 1970 cited in Patton 1987, p.20)

Examining perceptions of wellness necessitated the selection of a qualitative methodology that recognises cultural diversity and accepts the existence of myriad perceptions of social reality from which dominant cultural or sub-cultural views may emerge. Moorhead (1995) dismissess the assertion that qualitative research constitutes 'soft', and unreliable knowledge with little form or structure, in favour of the view that the very diversity and tension created by contradictions and similarities creates opportunities for study.

In the last three or four decades, qualitative research has evolved from a belief that individual or community norms are merely expressions of the norms and expectations of a wider system, to a belief that the individual has an active role in subjectively interpreting and interacting with the system in which it lives. Structural functionalism is concerned with identifying the components and processes of *systems* and their effect on the individual. This approach preceded an interest in phenomenology and ethnomethodology, which aimed to elicit the *meanings* individuals construct around the events in their lives.

Aspects of each of these methods are of value. For example, phenomenologists do not assume they understand what things mean to the people they are studying, rather viewing the process as one of discovery (Bogdan, Biklen 1992). An exploratory journey into another person's or group of people's conceptual world benefits from this approach.

Symbolic interactionalism focuses on the way interaction among people is shaped by the meanings and expectations the parties bring to settings. Symbolic interactionalists consider patterns of communications, symbols and signs as vehicles by which experience is mediated. Implicit in this philosophy is a belief in the existence of an 'insider' understanding of linguistic and cultural behaviour.

Ethnography, which will be described below, was selected as the most suitable framework within which to locate the qualitative components of this research.

3.11.1 The Selection of Ethnographic Research Strategies

The following section evaluates ethnographic research.

Ethnography can be described as discovery based, naturalistic observations of human behaviour or the:

> first-hand, intensive study of the features of a given culture and the patterns of those features (Gall, Borg, Gall 1996)

The aim of ethnographic research is to uncover the individual or community world view. The researcher, while never presuming to fully understand another person's cultural perspective, can produce valid interpretations, given an awareness of the group under observation.

> The qualitative evaluator must have sufficient direct, personal contact with the people and program being evaluated to understand what is happening in depth and detail. Second, the qualitative evaluator must be able to provide a meaningful context for what takes place and what people actually say... (Patton 1987, p.13)

The researcher builds general patterns from specific observations without imposing overt pre-existing expectations on the observations. This collection of data precedes any extrapolation of meaning, beyond linguistic translation. The approach to data collection is not a-priori in the sense that categories used for interpretation of raw data are not pre-established and rather are developed from the data. This contrasts with the hypothetical deductive approach of experimental designs, that requires the specification of main variables and the statement of specific research hypotheses before data collection begins (Patton 1987).

Since its emergence in the 1950s and 1960s, ethnography has faced accusations of being unscientific and imprecise (Atkinson, Coffey 1995, p4). However, the goals of ethnography (and of these studies) are different from those of natural science. Based on the belief that each individual's construction of social reality differs, so too ethnographic

observations are necessarily subjective. In counteracting accusations of 'spurious realism' (Hammersley 1990 p14), certain measures ensure that data is neither blindly accepted nor idiosyncratic; for example the interpretation of text is discussed with members of the community under observation (Pollard 1993).

The ethnographic approach selected for Studies 2.2, 3 and 4 places the researcher firmly within this research forum. The following section considers this in more detail.

3.11.2 The Insider/Outsider Perspective

The predominance of hearing researchers within the field of Deaf Studies has been a source of concern both to deaf researchers (e.g. Stinson 1993, Ridgeway 1995) and to hearing researchers (e.g. Hauser 1993). Some consider the potential risks of bias to be high in this situation, as a result of a lack of understanding of, or respect for, the perspectives of deaf people (e.g. Stinson 1993).

As a deaf researcher, Stinson (1993) praises the efforts of some hearing researchers, who attempt to become as personally involved as possible in the deaf community and deaf culture.

The traditional response from the predominantly hearing research community has been to devise a series of safeguards in order to represent aspects of deaf culture as accurately as possible, and as closely as possible to the way deaf people would do so. The use of qualitative content analysis software (section 3.25) to this end ensures that predominant themes emerge in a systematic and objective way. Meanings are aggregated in a way that maintains a close relationship to the text. In Studies 2.2 and 3 first language BSL users cross-checked the transcriptions of BSL into written English. In addition, the credibility of findings was discussed with deaf people. Such measures challenge the common practice of hearing researchers writing exclusively for a hearing audience (as criticised by Baker-Schenk, Kyle 1990).

Claims have been made that research done by hearing researchers is of less value. Without doubt cultural barriers do exist to prevent some 'insider' knowledge becoming

'outsider' (Akamatsu 1993). In turn, discontinuity between the researcher and the 'researched' has been used to suggest bias or question the subjectivity of work (Hauser 1993). Ethnographic theory posits that the relationship between observer and observed creates a legitimate dynamic constituting an important part of academic discourse.

While adopting certain safeguards against misinterpretation of text, the analyses presented in Chapters 6, 7 and 8 represent an informed outsider's perspective.

3.12 The Selection of an Open-Ended Interview - Study 2.2

The inclusion of a qualitative interview in Study 2.2 has many advantages. It facilitates both the collection of basic demographic information (e.g. lifestyle, or employment), while also allowing an opportunity to explore the conceptual world of each respondent within the sub-sample.

Previous research has highlighted the low average levels of English within the Conrad Cohort, therefore certain precautions were made in the selection of a type of questionnaire in order to maintain flexibility to potentially diverse language needs. In Study 2.2, the respondent was given the choice either of a deaf signing interviewer or a hearing signing or speaking interviewer.

To this end, the in-depth, open-ended format was chosen, and administered with the aid of an interview schedule. Topics listed in the schedule were not taken in strict order, and serve mainly as a basic checklist for the interviewer, providing a measure of standardisation across interview. The interviewer was able to adapt both the sequence and the wording to specific respondents, in the context of the actual interview.

Where the subject was unable to respond to a question, the interviewer was permitted to probe related areas.

3.13 Sampling Procedure - Study 2

Subjects were selected from the Conrad Cohort and the following selection criteria were used:

1) Hearing loss (as school leavers) of either less than 75dB or more than 85dB (hearing loss bands 1, 2, 4, 5[7]).
2) Resident in the South of England.

Initial co-operation was invited by letter. In many cases, members of the local deaf community were able to supply current addresses for those whose letters had been returned by the Post Office. A second correspondence to those whose response had been positive confirmed a date and requested a chosen method of communication for the interview. Table 3.1 details the response rate:

Hearing loss group	*Letters sent*	*Returned*	*Interested*	*Not interested*
4/5 (>90 dB)	*56*	*14 (25%)*	*11 (20%)*	*7 (13%)*
1/2 (<70 dB)	*90*	*31 (34%)*	*15 (17%)*	*6 (7%)*

Table 3.1 Subject response rate

A total of 21 subjects were interviewed.

3.13.1 Characteristics of the Sub-sample

In a longitudinal survey it is important to consider the extent of loss of subjects through refusals or failure to trace subjects, and how this effects the characteristics of the remaining sub-sample.

Rosenthal and Rosnow (1975) in the review of a large body of research have isolated characteristics found to consistently differentiate between (hearing) volunteer and non-volunteer subjects . Factors such as level of education, and religious denomination contribute to an inevitable biasing of a target population.

[7]Bands '1 or 2' represent hearing loss of up to 85 dB. Bands '4 or 5' represent hearing loss of over 96 dB.

The following section details points in the selection process that may have had an effect on the characteristics of the sub-sample.

Judging from the high number of Post Office returns, the initial tracing of subjects was problematic. After establishing contact, in at least four cases, co-operation was initially refused by a parent, either by letter or telephone. Although two of the four were subsequently interviewed, this represents a potential 'hidden bias'. In cases where local deaf people supplied current addresses, those whose names were recognised were likely to be active or prominent figures within the deaf community. Failure to understand the initial contact letter would bias in favour of those with higher levels of English. Although written in basic language, and checked by a deaf co-worker, confused responses could reflect the low level of English known to exist in this cohort (Conrad 1979).

3.14 Procedure - Study 2.2

The sub-sample selected was geographically disperse. For this reason it was often easiest to conduct the interviews in the respondent's home. Wherever possible the respondent was alone. However, particularly for parents of young children, conditions such as these were hard to fulfil, however the impact of distractions on the quality of data was minimal.

For each interview, instruments were administered in the same order to maintain interview conditions across the subject group.

Measures were taken to ensure that transcriptions created after the interview were as accurate as possible, for example those conducted in BSL were transcribed and cross-checked by a native BSL user.

3.15 Analysis - Study 2

3.15.1 Analysis - Study 2.1

There are two main strategies for interpreting quantitative standard measures of health status; approaches based on norms, and those based on criteria (Ware 1993).

Norms allow individual scores and group mean scores to be interpreted according to their position in relation to scores for a larger population. Such 'larger group' norms compensate for the lack of a 'gold standard' for health (Ware 1993 p.1430).

The sample in the current study, possessed no common variable other than hearing loss and owing to the dearth of health outcome data for similar populations, criterion variables were limited to age.

3.15.2 Analysis Study 2.2

The textual analysis techniques employed in the analysis of Study 2.2 are detailed in section 3.25.

3.16 Summary - Studies 1 and 2

The methodology selected for Studies 1 and 2 encompasses a twofold approach to the assessment of health. The first is quantitative and explores the performance of the subject group relative to wider population norms. While picking up many common symptoms of particularly emotional ill health, this method is limited in its ability to contextualise outcome measures.

The second approach is qualitative and begins to explore individual and community beliefs about health and wellness.

3.17 Study 3 (Sept.-Oct. 1996)

Quantitative methods employed in Studies 1 and 2.1 confirm other research findings pointing to relatively poor levels of mental health within the deaf population. The aim of Study 3 was to introduce a new framework within which to explore mental health, specifically, to explore the cultural interpretations of wellness. Study 3 was based therefore based on the following research question:

How is mental health and wellness perceived by deaf people and what factors affect this perception?

3.18 Methods of Data Collection - Study 3

In establishing the most appropriate research methodology for Study 3, two selection criteria were used. Firstly, that the methodology should allow independence from all established conceptual categories of health. Secondly, that the methodology should allow for collective cultural beliefs to emerge from the interaction of individual perceptions.

The following section describes, 'focus groups'; the method by which material in Study 3 was collected, and illustrates how focus groups differ from open group discussions.

3.18.1 Focus Group Discussions

Focus groups, or facilitated group discussions are an effective way of identifying collective ideas among a group of people. These may be facts, opinions, values and beliefs and may include latent beliefs or attitudes (O'Brien 1995). Focus groups can highlight differences in the worldview of a particular cultural group, and perhaps most importantly for this research, shed light and depth upon the complex sources from which and resources through which people sustain or modify their views about a health (O'Brien 1995).

The efficiency of focus groups lies in the fact that the group is encouraged to generate data which may differ from the sum of individual interviews. Focus group research depends upon the existence of a facilitator; he or she is responsible for steering discussion, ensuring each member's inclusion and for encouraging participants to provide reasons to back-up comments made in response to other individuals within the group (O'Brien 1995).

The presence of a facilitator in Study 3, especially an outsider to the deaf community provided a role that best suited ethnographic research principles. Within a more flexible group discussion, there is a risk of assuming an insider identity, thus losing the ability to explicitly and objectively control the direction of the group.

Intrinsic quality controls can be exerted on data collected; for example through checks and balances on members seeking consensus on 'false', extreme or dominating individual beliefs (Patton 1987). Views are expressed in an interactional context, consequently refinements, modifications and explanations can be provided, and areas of consensus or disagreement isolated (O'Brien 1995).

Relevant digressions are acceptable and discussion can be steered by occasional straightforward non-directive questioning. The use of a topic guide also ensures focus on the research agenda (Appendices 3,4,6).

3.19 Sampling Procedure - Study 3

Subjects for the focus groups were all members of the deaf community who identified themselves as culturally deaf. This was the primary selection criterion. Respondents within each of the two main groups shared other socio-economic features, that is, they were of similar age and occupational status.

3.20 Procedure - Study 3

Research with deaf people necessitated addressing two main procedural issues, firstly the need for smooth channels of communication and secondly, the need to record proceedings.

As the facilitator was a cultural outsider, with a different first language from group members, communication needed to be as clear as possible. A third party, in this case, a sign language interpreter was necessitated by the need for accurate and meaningful discussion.

In the recording the focus group in sign language options such as note-taking or spontaneously voicing over sign, though feasible were thought to be slow. These methods also involve more human resources than filming the group to transcribe at a later date. Filming therefore took place in all focus group research.

3.21 Study 4 (March - April 1996, May - June 1996)

Study 4 attempted to trace one root in the evolution of a system of beliefs about wellness. The study of a separate body of professional people, closely associated with the deaf community affords the opportunity both to document outsider views on deaf wellness and also to consider the interaction between insider and outsider beliefs.

The aims of Study 4 were therefore twofold:

1) To provide another perspective on deaf wellness, that of a professional group of hearing people working within the community.

2) To examine the significance of such beliefs in the wellness of the deaf community.

3.22 Method of Data Collection - Study 4

In accordance with ethnographic research principles, a type of qualitative interview was sought which satisfied the need for flexibility whilst ensuring similar domains were covered between respondents.

3.22.1 The Selection of Structured Open-Response Interviews

While focus group discussion provides rich data, the feasibility of arranging focus groups among a geographically dispersed respondent pool precluded this as a method of data collection.

Individual interviews may be carried out with varying degrees of structure. Unstructured methods of interviewing were inappropriate for a study of this nature. An examination of a professional culture while drawing upon subjective experience, leans on common perceptions. In order to maintain a degree of uniformity it was important to ensure each individual, while divulging their specific experience was led through similar aspects of their working life. At the other extreme, a rigidly structured interview not only presumes knowledge about the type of information respondents will provide but does not allow insight into subjective interpretations of professional culture.

The choice of a 'structured *open-response* interview' ensured that standard areas of investigation were covered across all the interviews, while a low degree of structure, and a preponderance of open rather than closed questions allowed both flexibility in styles of response, and an opportunity for the respondents' perceptions to emerge. This method of interviewing was particularly suitable for situations in which there was uncertainty as to the nature of information participants would be able to provide.

The 'structured open-response interview' lies between the qualitative research interview and the structured interview, relying on an interview schedule while maintaining a comfortable degree of flexibility in it's administration, and drawing on the possibility of using prompts and probes (Patton 1987).

Within this style of interviewing, the interviewer remains part of the research process, rather than distinct from it, but is able to control the interview where necessary. In accordance with ethnographic principles, the interviews were facilitated by the researcher's familiarity with the subject area.

3.23 Sampling Procedure - Study 4

Having considered the existence of cultural beliefs surrounding wellness, it is possible to isolate several groups of people who have both their own perception of deaf people and deaf wellness, and who appear to contribute to the perception of health within the community. They are the teachers, medical professionals, parents and others who have responsibility for deaf people at various points in their life.

Preliminary discussion with deaf people led to the emergence of one particularly influential professional group who are historically viewed as the gatekeepers to deaf people's health, that is, the professionals involved in social welfare.

3.24 Procedure - Study 4

In a situation in which both respondent and interviewer are hearing, the only procedural concern to ensure a high quality audio recording of the interview, from which to create a transcription.

3.25 Analysis - Studies 2.2, 3 and 4

The creation of transcripts of both interviews and focus groups requires procedures that fulfil rigorous checks on validity. The use of software in the management of large quantities of data facilitates analysis through the coding and sorting of segments of text. One such ethnographic content analysis software package is The Ethnograph v4.0 (Seidel, Kjolseth, Seymour, 1988) and this was chosen to analyse all qualitative data.

In considering the best method to analyse data, the nature of the data collected suggested template analysis would be the most appropriate. Template analysis differs from classic content analysis in that emergent themes are interpreted qualitatively rather than quantitatively.

Quasi-statistical content analysis would have been possible, whereby units of measurement e.g. themes or words were categorised (Casell, Symon 1994), however this method is firmly located within the quantitative logical-positivist tradition, concerned with hypothesis testing, generalisability and the separation of the researcher from the data for the sake of objectivity. Data collection within the deaf community often takes place in a language other than that in which it is analysed. For this reason, quasi-statistical methods, which lean heavily on linguistic characteristics was thought inappropriate.

'Editing techniques' (Casell, Symon 1994), whereby meaningful segments are selected and reduced to reveal the 'interpretive truth' (e.g. Glaser, Strauss 'grounded theory' 1967 cited in Bridge 1995) would have necessitated a purely naturalistic style of data collection relying heavily on exact language rather than the conveyed meaning.

A template model of analysis was therefore employed which is based on the development of a 'codebook' (Crabtree, Miller 1992 in Cassell, Symon 1994 p26). The codebook consists of a number of categories or themes relevant to the research question. Sets of codes are developed in response to an initial analysis of text and typically revised several times throughout the analysis of text.

3.26 Validity, Reliability and Relevance

Empirical tests of validity and reliability within quantitative studies can be carried out with relatively straightforward procedures. Within qualitative research and particularly ethnographic studies, measures of reliability are questioned on the basis that qualitative research does not have the same drive for objectivity. Measurements of accuracy demand alternative criteria. Hammersley (1990) considers both validity and *relevance* to be the most important assessment criteria in qualitative research.

By validity he refers to:

> the extent to which an account accurately represents the social phenomena to which it refers (Hammersley 1990 p59)

In response to the debate about cultural diversity and the existence of any true culture, Hammersley (1990) proposes that validity be based on 'subtle realism' whereby:

a) No knowledge is certain, but knowledge claims can be judged reasonably accurately in terms of their likely truth.

b) There are phenomena independent of us as researchers or readers of which we can have knowledge (although only in a defined way) Hammersley (1990 p61)

In qualitative research, determining whether a study has examined what it claims to have done, necessitates focus on interpretation, the latter being appropriate primarily to quantitative research (Cassell, Symon 1994).

In Studies 2.2, 3 and 4, standards of validity and relevance were maintained in the following ways:

1) In the initial selection of an ethnographic approach which allowed the researcher to have a legitimate relationship with, and interpretation of the data.

2) By ensuring that where possible, objective procedures were employed in the *sorting* of data, specifically through the use of The Ethnograph software package (Seidel et al 1988).

3) By cross checking transcriptions and interpretations of BSL with a native BSL user.

4) By triangulation strategies. Study 2.2 offered an opportunity to directly compare quantitative and qualitative findings. This will be examined in section 5.10.

3.27 Summary - Studies 3 and 4

Studies 3 and 4 explore the cultural construction of wellness. Importance is attached to the location of the researcher or observer within the ethnographic research process. The use of focus groups and structured open response interviews are introduced as the most appropriate form of data collection. Finally the assessment of validity, reliability and relevance in qualitative research are considered as procedures for assigning value to interpreted findings.

Chapter 4: Psychiatric Referral Patterns within the Conrad Cohort

4.1 Introduction

The aim of Study 1 was to investigate the rates of referral within the Conrad Cohort with respect to mental ill health. Only those people referred to the three Specialist Units for Mental Health and Deafness are included in the findings detailed below.

In addition, a profile of the group of people referred to the psychiatric units was constructed from two sources, firstly from data collected in the original study (Conrad 1979), and secondly from psychiatric case notes supplied by the psychiatric units.

The following section will detail the selection procedures employed in the initial study. It will then present the findings of Study 1.

4.2 Subjects: The Conrad Cohort

The initial study of young deaf people took place between 1974 and 1976, when subjects were between the age of 15-16½ years and at the latest point in their statutory education (Conrad 1979).

All secondary units on NDCS[8]and local authority lists were approached, and those with children of the correct age were interviewed and tested. In total, 573 young people were tested, involving 39 Schools for the Deaf and 48 Units within mainstream schools. Certain other schools were excluded for the following reasons: one school refused to be tested (approximately 10 children); one school and a department for the multiply handicapped (29 pupils) were omitted, together with a school for the maladjusted (2 children), on the grounds that testing would be too difficult. One unit refused testing on administrative grounds (4 children), and one school was left out due to administrative difficulties for the research team (3 children).

Thus the total number tested represented the total population available. No more than 10 pupils in total were omitted due to ill health and other factors. On this basis the study

provided a realistic picture of the performance of a near total cohort of deaf and hearing-impaired school leavers in England and Wales.

In addition to the collection of comprehensive demographic data, instruments were administered which established achievement ratings in many educational and cognitive domains.

The findings of the original study were negative and alarming, and brought into question whether teaching methods, using 'speech only' were appropriate for deaf children. Despite a normal distribution of intelligence, the deaf school leavers in this Cohort had an average reading age of 8¾ years, and performed poorly in speech and speech reading (Conrad 1979). At the time of Study 1 members of the Conrad Cohort were aged between 34-36 years old.

4.3 Study 1

In order to examine the rates of referral within the Conrad Cohort for mental health problems, co-operation was established with the specialist mental health service providers for deaf people.

4.3.1 Supra-Regional Mental Health Services for the Deaf

There are three Supra Regional Psychiatric Units for deaf people in Britain, all situated within NHS Trusts (although only one existed at the time of Conrads' study). Each Unit has either one or two Consultant Psychiatrists and a team of deaf and hearing support staff with varying knowledge of deaf people and BSL. The three Units are:

1) *John Denmark Unit*, Salford Mental Health Services, NHS Trust.
2) *National Deaf Services,* within Pathfinder Mental Health Services NHS Trust (London).
3) *Denmark House*, Queen Elizabeth Psychiatric Hospital, South Birmingham Mental Health Services, NHS Trust.

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[8]National Deaf Children's Society.

In addition to out-patient and in-patient facilities, several regular satellite clinics are held in less accessible areas of the country.

Full co-operation was obtained from each unit, and the three Consultant Psychiatrists freely volunteered time to impart advice and assistance. The research design specified no patient involvement but necessitated retrospective examination of each patient database. Ethical Approval was obtained from relevant Local Health Authorities. It is of significance that one of the units was considerably newer and smaller than the other two. The Consultant Psychiatrist at this Unit, having been in position since the inception of the unit, felt confident that approval could be obtained from the potentially small number of individuals concerned.

The study enabled two important sources of information to be brought together: firstly the original data on educational and cognitive achievements and secondly, psychiatric case notes detailing the nature of any psychiatric disorder. The procedure for the collection of both sets of data will be examined below together with a summary of measures included.

4.3.2 Collection of referrals data

Visits of two or three days took place to each of the two larger units. Names on the psychiatric database were matched against names of those in the cohort. For each positive identification, two types of data were obtained:

1) An ICD-9 diagnosis[9], with dates of in-patient or out-patient admission. In the majority of cases, psychiatric diagnosis was stated in the case file, and confirmed by the Consultant Psychiatrist. Where diagnosis was not stated, the Consultant Psychiatrist gave a diagnosis based on his or her knowledge of the individual.

The Consultant Psychiatrist attached to the third smaller centre was able to identify patients known to her from the total list of those in the cohort. Each patient was contacted and gave consent for information to be made available to a researcher on the proviso that individuals concerned were not identifiable in later stages of research.

There was a surprising movement of patients once in the system, between the three Units, and care had to be taken to avoid recording patient information twice.

Rates of referral together with patterns of diagnosis within the Conrad Cohort were compared to national statistics for the general population. It is hard to ascertain the precise figures for the hearing population as the health care statistics are complex and do not always provide the most meaningful categories for comparisons. Unfortunately no data was available for comparable *life span* referral patterns in general population samples. For this reason, referral patterns for the year 1991/2[10] were examined and the comparisons eventually drawn represented the closest possible match for both year of admission and age of patient.

One further source of comparative data was used. Statistics were available for psychiatric referrals in the general population which were matched closely for age. This data, however was for the year 1986.

Data for the general population therefore comes from two sources;

i) Hospital Episodes Statistics 1991/2 and 1992/3.

ii) Mental Health Statistics for England 1986.

2) From patient notes, a case history profile was obtained of the individual. Due to the varying quality and content of these notes, data was not standard across cases. Where possible it included presenting traits, family and school background, levels of communication, and mental illness in the family. This profile was accepted as the qualified, yet nevertheless subjective observations of the psychiatrist. An examination of psychiatric case notes allows insight into the common experiences of those referred.

4.4 Findings from referrals data

Of the total of 573 people in the original sample, 33 people (5.76%) were referred to one of the Specialist Units for Mental Health and Deafness during the year 1991/2. The

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[9]International Classification of Disease, World Health Organisation 1988, 9th Revision.

pattern of diagnosis within this group (n=33) is as shown in Table 1 and the rate compared with statistics for the general population (rather than exclusively with the hearing population). Statistics relating to those in the Conrad Cohort have not been removed from total population data. However, their size relative to that of the total population renders the effect of this omission negligible.

	Deaf (Conrad Cohort)		'Hearing' (General population)	
Category	Number	% of those referred	Number	% of those referred
Educational/learning difficulties (deaf only)	4	12.1	-	-
Mental retardation (hearing only)	-	-	29,126	10.5
Psychoses	9	27.3	88,390	32
Neuroses	4	12.1	25,891	9.4
Personality/behavioural	16	48.5	13,498	4.9
Other	-	-	119,350	43.2

Table 4.1: Referral patterns among deaf people to Supra Regional Mental Health Units by the age of 35 years and hearing people to non-specialist psychiatric services[11].
(Statistics represent consultant episodes for mental illness 1991-2).

The data in Table 4.1 for the deaf population is based on ICD 9 diagnoses, but note 'Educational difficulties' (V62.3) and 'Mental Retardation' (317, 318) are grouped together. The category 'Psychoses' included the following subgroups only: 'Schizophrenic psychoses' (295), 'Affective psychoses' (296) and 'Other non-organic psychoses' (298). The category 'Neuroses' included 'Neurotic disorders' only (300). 'Personality/Behavioural disorders' referred to 'Personality disorders' (301), 'Sexual deviations and disorders' (302), 'Specific non-psychotic mental disorders following organic brain damage' (310), and 'Disturbance of conduct not elsewhere classified' (312).

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[10]Years represents April 1991-April 1992.
[11]The data for hearing people comes from the Hospital Episodes Statistics for England 1991/2 (Table 4, p76 and Table 9, p220).

The hearing clinical sample totals 276,210. This figure is a combination of 'Mental illness' (222,378) and 'Mental handicap' (53,832). The latter was included to enable the estimation of a percentage for 'Mental retardation'. For the category 'Mental retardation', ICD 9 categories 'Mild mental retardation' (317) and 'Moderate mental retardation' (318) only were used, to reflect the deaf clinical sample. Similarly, the category 'Psychoses' includes the following subgroups only; 'Schizophrenic psychoses' (295), 'Affective psychoses' (296) and 'Other non-organic psychoses' (298).

The overall rate of referral is much higher than the expected figure for the general population. Drawing on the selection criteria employed in the original formation of the Conrad Cohort, other surprising patterns emerge. Four people were diagnosed as having educational or learning difficulties. The remaining individuals were diagnosed as displaying psychotic or neurotic behaviour or as having a behavioural or personality disturbance. Since Conrad excluded those with severe emotional or behavioural difficulties in childhood, and those with severe learning difficulties, these are surprisingly high figures.

The striking difference in these figures is for disorders relating to personality or behaviour. Although there are similar proportions of psychotic and neurotic disorders, deaf people are much more likely to be referred with disturbance of personality or behaviour.

Referrals for all mental illness during 1991-2 for those aged between 15 and 44 years were almost three times greater in the sample of deaf people. For those who presented with personality and neurotic disorders the rate was almost six times greater in the deaf sample compared to the general population (in this age category); with affective and non-organic psychotic problems, the referrals were roughly three times more.

Table 4.2 indicates the pattern of referrals for the years 1991-2 in England and Wales matched more closely (although not exactly) for age.

Category	Deaf referred (34-36 years) % of school leaver group N=573	Hearing referred (25-35 years) % of population N=6,717,478	Multiple of deaf greater than hearing
All mental illness (25-35 yrs)	1.75	0.117	14.6 times
Schizophrenia	0.524	0.013	40.3 times
Affective Psychoses	0.175	0.008	21.9 times
Other psychoses	0.175	0.006	21.9 times
Neuroses	0.349	0.016	21.8 times
Personality/ behaviour	0.175	0.013	13.5 times
Other	0.359	<0.001	12 x 10^3 times

Table 4.2: Patterns of referral matched more closely to age[12].
('First admission' for general population in 1986, against all noted referrals for sample of deaf people in 1991-2.)

The clinical sample for the general population data totals 7,877 ('All diagnoses').

In accordance with ICD-9 classifications, the following categories are used.

Schizophrenia refers to 'Schizophrenia, Paranoia' (295, 297), 'Affective psychoses' (296), Other Psychoses refers to Other Psychoses (including Drug Psychoses) (292-294, 298-299), Neurotic Disorders (300), Personality/Behaviour Disorders (301-302, 307-309, 312-315), Other Psychiatric Conditions (All other codes).

Where more precise age statistics exist (25-35 years), the incidence is even higher. Within the cohort, the proportion of deaf people experiencing personality/behavioural and neurotic problems was much higher than hearing people in a similar age bracket.

4.5 Profile of the Referred Group

Clearly the incidence of referral to specialist psychiatric units is high, and without doubt higher than that of the general population. The sub-sample of those referred is small

(n=33), nevertheless, certain preliminary observations are presented which go some way to creating a profile of this group.

The number of subjects in both the cohort and the group of those referred vary across the analyses carried out. This is due to the selection procedures employed in the original study. Complete sets of data from the original study in 1974-6 were therefore unavailable for six of those referred, leaving complete data for only 27 of the 33 subjects. This was significant in some analyses.

4.5.1 Demographic data

4.5.1.1 Gender

Within a small sub-sample the proportions below did not differ significantly from the figure for the total cohort (47% and 53%, male, female respectively).

Gender	% Cohort (n=468)	% Referred Group (n=33)
Male	47	57.6
Female	53	42.4

Table 4.3: Gender distribution within the referred group

4.5.1.2 Home background

Within the total cohort a slightly higher proportion (78.8%) were living with both parents, and slightly lower (20.3%) proportion lived in other situations e.g. with one parent or guardian, in comparison to the referred group.

Home Background	% Cohort (n=468)	% Referred Group (n=27)
2 Parents	78.8	66.7
Other	20.3	33.3
Unspecified	0.9	-

Table 4.4: Home background within the referred group

[12]The data for general population comes from the 'Mental Health Statistics for England' (1986) Booklet 12 'Mental Illness Hospitals and Units in England', Table A 5.1.

4.5.1.3 Socio-economic background

Within the group of those referred for which the original data was available (n=27), the following pattern of parental socio-economic background was found, distribution differing only slightly from that of the Cohort (Table 4.5).

Parents Employment	% Cohort (n=468)	% Referred Group (n=27)
Professional	9.8	7.4
Manual	39.5	37
Other	40.9	37
Unknown	9.8	18.5

Table 4.5: Socio-economic background of parents of those in the referred group

4.5.1.4 Home Language

For all those known to the Psychiatric Units the only language used at home by parents had been English. This compares to 95.5% of total cohort reporting English and 4.5% reporting the use of sign language as the language used within the family. No other language was given as a first language and the existence of a second language within the home was not explored.

Home Language	% Cohort (n=468)	% Referred Group (n=27)
English	95.5	100
Sign Language	4.5	-
Other	-	-

Table 4.6: Language used at home within the referred group

4.5.2 Data relating to deafness

4.5.2.1 Cause of deafness

Any aetiological details would leave many categories with single entries, therefore the cause of deafness has been grouped into three categories: hereditary deafness, acquired deafness and unknown (Table 4.7).

Cause of Deafness	% Cohort (n=468)	% Referred Group (n=27)
Hereditary	27.3	18.2
Acquired	30.8	45.4
Unidentified	41.9	36.4

Table 4.7: Cause of deafness for those in the referred group

4.5.2.2 Hearing Loss

Hearing loss was evenly distributed throughout the group (Table 4.8):

Sample	<65dB	66-85dB	86-95dB	96-105dB	106+dB
Cohort (n=441)	30.4	24.3	12	18.6	14.7
Referred Group (n=27)	14.8	22.2	25.9	22.2	14.9

Table 4.8: Hearing Loss Distribution in the group of those referred against the total cohort of school leavers.

When better ear average hearing loss is divided into two categories, above or below 85 decibels (dB), two groups are created; those with hearing loss of less than 85dB[13] and those with a loss of between 86 and 120 dB[14]. There was no significant difference in distribution of hearing loss (Chisquare = 4.17) between the cohort and the referred group. However, although there was no significant difference in distribution of hearing loss, the percentage of individuals in each group with greater hearing loss, that is with hearing loss over 86dB differed (45%, and 62% for Cohort, and referred group respectively). These results suggest that the referral group was 'deafer' than the total cohort.

4.5.2.3 Additional handicap

In the original study, additional disability could fall into one of two categories. In each case the handicap was significant with respect to education. It therefore excluded for example physical handicap, unless it interfered with schooling. 'Handicap-1' represented the basic and required category. It included young people who at the time suffered, for example, from asthma, were epileptic, or spastic. 'Handicap-2' referred to handicaps

[13]This group is more likely to be described as 'mildly', 'moderately', or 'severely' deaf and typically use residual hearing (and hearing aids) to facilitate both the reception and production of speech.

such as slight spasticity, club foot, or mild allergies. It should be remembered that those with extreme emotional or behavioural problems or who were multiply handicapped had already been excluded from the Cohort (Table 4.9).

Additional Handicap	% Cohort (n=468)	% Referred Group (n=27)
No additional handicap	80.8	63
Additional handicap 1	10.4	25.9
Additional handicap 2	8.8	11.1

Table 4.9: Existence of additional handicap within the referred group

4.5.2.4 Type of school attended

The proportion of subjects in both the total Cohort and the Referred Group attending either a PHU or Deaf school, as day or residential students was very similar (Table 4).

ype of school	% Cohort (n=468)	% Referred Group (n=33)
i) PHU	23.3	27
ii) Deaf school	76.7	73
% Day	36.8	37.5
% Residential	63.2	62.5

Table 4.10: Type of school attended by those in the referred group

4.5.3 Cognitive and Educational Data

Data on academic and other performance scales constituting the original study by Conrad (1979), were held at the Centre for Deaf Studies, University of Bristol. The following tests were completed in the original cohort study.

4.5.3.1 Intelligence

The test chosen was Raven's Progressive Matrices (1960), a non-verbal test of intelligence. The results presented below are raw scores. A statistical test of difference (t-test) between the two groups indicated that the mean for those referred to the psychiatric

[14]This group constitutes the 'profoundly' deaf, whose degree of deafness more often prevents the use of significant residual hearing in communication.

units (N=27) differed significantly from that of the whole group of school leavers (N=348, $p<0.001$), (Table 4.11).

Sample	Mean	S.D.
Cohort (N=348)	39.95	10.80
Referred Group (N=27)	31.26	14.14

Table 4.11: Intelligence: mean and standard deviation (S.D.) for raw scores on Raven's Progressive Matrices

Closer examination of the raw scores of the Raven's Matrices test of intelligence indicates that nine subjects within the group of those referred (n=27) had extremely low intelligence scores (i.e. raw score <20, Raven et al 1979). This information is important to our understanding of those most vulnerable to mental illness.

4.5.3.2 Reading

The reading test used was the Wide-Span Reading Test (Brimer 1972). Scores were converted from a basic nominal scale score to a reading age. Scores for reading differed significantly between the school leavers and those referred to the units, indicating a lower level of literacy in those referred. ($p<0.05$), as displayed in Table 4.12.

Sample	Mean	S.D.	Reading Age
Cohort (N=351)	20.08	21.15	9.33
Referred Group (N=27)	10.85	17.32	8.16

Table 4.12: Mean and standard deviation (S.D.) of nominal scores for reading, and equivalent reading age in years (Wide-Span Reading Test).

4.5.3.3 Speech Comprehension

The modified Donaldson Lip-reading Test (Montgomery 1968) was used. For the comprehension of words, the mean score (out of 38) of all those referred was lower than the whole cohort ($p<0.1$, and $p<0.02$ respectively) although not significantly so (Table 4.13).

	Speech Comprehension-words	
Sample	Mean	S.D.
Cohort (N=351)	29.53	8.47
Referred Group (N=27)	27.96	9.32

Table 4.13: Mean and standard deviation (S.D.) scores for speech comprehension (Donaldson Test, maximum score =38).

4.5.3.4 Speech Intelligibility

This measure included ratings both of spontaneous speech and scaled scores of formal utterances. No single, previously standardised test was used, however the testing drew upon a number of features of other published tests. Scores represent the number of items that were rated intelligible by a listening panel. The scores for intelligibility of words are out of a maximum score of 20[15] (Conrad 1979). There was no significant difference in the level of intelligibility between the total Cohort and the group of those referred (Table 4.14).

	Speech Intelligibility – words	
Sample	Mean	S.D.
Cohort (N=344)	6.06	6.71
Referred Group (N=27)	3.09	4.21

Table 4.14: Mean and standard deviation (S.D.) scores for speech intelligibility

4.6 Findings from patient case notes

Case notes were available for 31 of the 33 people referred to the psychiatric units. While each individual's situation is unique, it is possible to identify types of behaviour common to many of the subjects, for example inadequate social skills or depression. Areas most

frequently mentioned in the case notes constitute comments relating to communication, to aggressive and/or violent behaviour and to the family's negative reaction to the deaf person.

Comments reported from psychiatric case notes represent the subjective evaluation of the psychiatrist. In some cases, professional judgement is likely to have been influenced by a psychologist's report or the observation of other professionals, such as a Social Worker.

4.6.1 Communication

Of the group of those referred for whom case notes were available, 24 (77.4%) either self reported communication problems within the family or were assessed as having communication problems by the psychiatrist. The following comments relate to communication and hint at the long term and often far reaching effects of problematic communication.

> Generally unhappy memories of childhood with parents not understanding deafness. No signing or finger-spelling, only idiosyncratic gesture.
> (Male, diagnosed Paranoid Psychosis)

> Social worker believes the whole problem to be a combination of high motivation and enthusiasm, but low ability and the reality of deafness and poor communication within the family.
> (Male, diagnosed Paranoid Schizophrenia)

> No intelligible speech and limited vocabulary in BSL, leading to consequent lack of general understanding. With family, he lip-reads a little but prefers things to be written down with hearing people...he lives with his parents and younger brother but only has formal contact with them due to communication problems.
> (Man, diagnosed Personality disorder)

> Orally educated, severe communication difficulties, signs and spells but in a limited way due to poor language and educational retardation.
> (Male, diagnosed as having a Personality disorder)

---

[15]Ten sentences with two items identified in each sentence.

Many of those reported to have had communication problems were described as having 'some' signing skills by the psychiatrist. In many cases however, signing skills appeared either to be minimal or acquired late in life.

4.6.2 Aggression and Violent Behaviour

Of those for whom case notes were available, 25 (78.1%) had aggressive or violent outbursts.

> Increasingly aggressive since adolescence, egocentric and problematic to family, needs to be humoured all the time or has temper tantrums that lead to violence...she is extremely naive which has resulted in severe isolation and an unhappy unstimulating life.
> (Female, diagnosed Personality disorder)
>
> X always prone to aggression, first to sister and then to parents if slightest whims are not satisfied.
> (Male, diagnosed Personality disorder)
>
> Constant friction at home resulting in physical attacks on parents...parents report him to be almost unmanageable at home, violent when parents attempted to enforce any order, frequently hits mother and recently broke three of brothers fingers.
> (Man, diagnosed Personality disorder)

It appears that for a very high proportion of those referred, aggression was the predominant if not sole response to unacceptable situations.

4.6.3 Family's negative reaction to deafness

In 10 of 31 cases (32.3%), comments are made which strongly suggest that the family's negative reaction to their child's deafness was of significance and relevant to the aetiology of psychiatric illness. For example:

> Father refuses to accept deafness...she believes she was an unwanted child, born before parents were married, and feels father's rejection strongly
> (Female, diagnosed Neurotic depression).
>
> Believes mother never loved her and treated her differently because of her deafness
> (Female, diagnosed Neurotic depression)
>
> Mother feels guilty about deafness and father takes no notice of X
> (Male, diagnosed Non psychotic mental disorder).

4.7 Discussion

The higher rate of referral for all mental illness within this cohort confirms patterns noted by other research, that is, that deaf people have a higher rate of referral for psychiatric disorder than do hearing people. The rate of referral within the Conrad Cohort may be up to 14.6 times as high as that of the hearing population.

Although the sample size is relatively small, when the referral details are added to existent data on those in the cohort, certain patterns emerge which combine to create a profile of the developmental environment. Those referred were more often found to have been raised in families with one parent or guardian rather than two, and again a higher proportion were raised in families with no other language than English. There was also a slightly higher rate of additional handicap in those referred.

Scores for various aspects of language and communication fluency are extremely valuable in assessing the skills with which individuals address their own social and emotional development. Reading levels within the Cohort were very poor i.e. the median reading age was 7½ years. Conrad (1979) comments that the cohort's average reading age of a nine-year-old left 'too many deaf children close to illiterate'. In those with a hearing loss of 86dB+, 50% were described as having a reading age of a seven-year-old. Within the total Cohort, those people with a hearing loss of under 85dB, 25% performed at the same level as a seven-year-old hearing child. Within the group of those referred, the mean reading age was even lower than the score for the total group of school leavers.

Although there was no significant difference in the ability to articulate spoken English, there were important differences in other aspects of communication. For example, the group of those referred found it more difficult to understand through either lip-reading or residual hearing what was being said to them. We can speculate that the effect that language deprivation had on their psychological development was profound, at least affecting socialisation and personality development.

Study 1 draws together two sets of retrospective data that shed light upon the relevance of these statements to those in Conrad Cohort. Firstly, data on the language and communication ability of the referred group as school leavers and secondly, psychiatric case note reports. Without establishing control procedures for other variables, it is impossible to claim a *direct* causal relationship between language/communication skills alone and mental health outcome. However, collating such data strongly supports the belief that poor language skills are likely to have significantly affected the quality of personal and social development and are likely to have significantly contributed to a poor mental health in adult life.

This situation was arguably exacerbated by a predominantly oral communication policy. In an attempt to normalise deafness, professional advice to parents of deaf pre-school children was to treat children as normally as possible, using as much speech as possible, and to avoid sign language. Similarly at school, the oral method prevailed throughout the years in which all those in the Conrad Cohort were in full time education. Research has demonstrated that many of these children, whose intelligence scores fell within the normal range, struggled to acquire English to any functional degree (Conrad 1979, Gregory 1995).

These results reinforce the findings of the review of case notes. Aggressive outbursts, reported in three-quarters of the case notes are often associated with feelings of intense frustration. The cases above describe individuals with a low threshold for aggression and violent behaviour. Aggressive outbursts precipitated by intense frustration are likely to result from the inability to communicate or to be understood.

Similarly, negative responses to deafness from within the family could be expected not only to compound existent communication barriers but to reinforce negative aspects of self-perception.

A consideration of the nature of the presenting problem, further strengthens the belief that the roots of certain types of mental disorder lie in disrupted socialisation. Although the referral rate for all types of mental disorder was greater in the deaf cohort, the number of

referrals for behavioural and personality problems was greatest of all. These findings should be treated with some caution because services for hearing people with mental health problems are less likely to offer treatment to people with personality or behavioural problems. Nevertheless problems of personality and behaviour are more often thought to have strong roots in the early developmental environment (Chapter 1).

While a distinction is maintained between a pathological behavioural or personality disorder and behaviour commonly found in deaf people, it is perhaps appropriate to identify similar socialisation conditions. An early problematic developmental environment is known to have disruptive effects on socialisation and development. With this in mind, one can interpret the high rate of referral for personality/behaviour disorders together with references to violent or aggressive behaviour, as being similarly influenced by the language deprivation of the developmental environment.

A pattern emerged between mental health and lower intellectual ability. The relationship between lower intelligence and mental health is often compounded by factors such as the existence of additional disabilities. For the purpose of analysis, two groups were created within the group of those referred. The first group consisted of those with lower intellectual ability (n=9). This group had the same, if not poorer, language and communication skills than the whole group of deaf school leavers. They presented with very similar problems to the referred group, as the psychiatric notes reveal.

The second group consisted of those of intellectual ability within the normal range (N=18). Having excluded those with lower I.Q scores, the remaining sample had a normal distribution of intelligence, that is, they were no less intelligent than a comparable group of hearing people. This group, who went on to be diagnosed as suffering from a mental disorder, also had poor language levels and communication skills that would have left them poorly equipped to communicate orally.

From this research, a picture illness within the deaf community emerges. Within the hearing population, a normal distribution of mental health suggests that the bulk of the population experience moderately good mental health. Within the deaf community the

distribution of ill-health can be perceived to have shifted, with many more people experiencing poorer health and a higher rate of referral for mental health problems.

It is perhaps appropriate to reiterate that deaf people's rate of service take-up is much lower at every stage of the passage to specialist psychiatric care (Checinski 1991). Therefore the picture of mental health may be much worse. Within this interpretation, those people referred to specialist units represent only a small proportion of those whose level of mental health falls into the lower end of the distribution of health within the deaf community. Study 2 goes on to explore the prevalence of mental ill health among those members of the Cohort not referred to the psychiatric services.

Chapter 5 Indicators of Health within the Conrad Cohort- Study 2

5.1 Introduction

This chapter reports interviews with a sub-sample of the Conrad Cohort (see section 3.4.1). Respondents are members of a cohort about which much is already known. Studies of their cognitive and educational achievements have helped construct an accurate picture of the tools with which a group of deaf school leavers began adult life. In the years that followed, a higher than expected proportion of those in the cohort were referred either as in-patients or as out-patients to Psychiatric Units for the Deaf. The following study addresses the mental health of the cohort in general. Ascertaining the extent of psychiatric morbidity within the complete cohort was not feasible due to the constraints of time and budget; however Study 2 considers the experiences of a sub-sample of the cohort.

The process of creating a sub-sample, as section 3.12 outlines, is necessarily selective; therefore generalisations from the findings of Study 2 are tentative. Nevertheless caution should not overshadow the fact that cohort studies by their very nature offer the opportunity to examine members of a group who have an enormous amount in common and about which much is known.

The selection of standard measures of mental health allows a psychiatric profile of the sub-sample to be established. Chapter 1 discussed the need for sensitivity in the use of standard measures in cross-cultural settings. This issue becomes particularly pertinent in Study 2 which presents quantitative scaled scores alongside qualitative interviews. Data collected from respondents elucidates some of the processes and mechanisms used by an individual in order to maintain a state of health or conversely ill health. Such qualitative findings provide insight into the pathways to a present state assessment. Section 5.7 explores some of the resources that enable some people to negotiate stress in a particular way and features of experience that put others at a disadvantage.

5.2 Subjects

The design of the study has been outlined in 3.12. Those interviewed (n=21) were members of the Conrad Cohort.

5.3 Procedure

Details relating to the interview setting have been reported in section 3.14. The interview was in two parts:

i) Semi-structured interview (45 minutes - 1½ hours).

ii) Standard measure assessments: GHQ-30, SF-36 (<1 hour).

As described in section 3.12, each respondent established his or her preferred method of communication for the interview. Table 5.1 displays the patterns of communication choice for each hearing loss band.

Hearing Loss Band	*Sign Language*	*Spoken Language*
1 or 2 (<75 dB)	-	11 (52%)
4 or 5 (>85 dB)	6 (29%)	4 (19%)

Table 5.1: Subjects' hearing loss against preferred method of communication (figure in brackets refers to percentage of total sub-sample) (n=21).

The interviews in sign language were recorded on video camera. There were no objections to this filming. Spoken interviews were recorded on audio cassette. Transcriptions of the interviews were produced by the researcher from both the audio recorded (n=15) and video-recorded (signed) interviews (n=6) (see section 3.13). Consultation with the deaf interviewer enabled both a clarification of the meaning in sign language, often necessary due to regional sign variation, and an opportunity to develop an appropriate cultural interpretation of responses.

5.4 Results

5.4.1 GHQ-30

All questionnaires were completed in full (n=21). The four-point response scale was scored in two ways. The first 'GHQ scoring' represents the traditional method of weighting the columns 0,0,1,1, (see Appendix 3 for GHQ schedule). This avoids the problem of 'middle users' (Goldberg,Williams 1988). An alternative method of scoring was introduced to allow for the response 'no more than usual' to be interpreted as an indicator of chronic illness (Goodchild, Duncan-Jones 1985 cited in Goldberg, Williams 1988). Known as Chronic or CGHQ (Goodchild, Duncan-Jones 1985, cited in Goldberg, Williams 1988) this second method divides test items into those where agreement indicates illness (negative items e.g. feeling constantly under strain) and those where agreement indicates health (positive items e.g. enjoying day to day activities). Scoring is either 0,0,1,1 (positive items) or 0,1,1,1 (negative items). The authors of the alternative method of scoring claim that CGHQ gives more normally distributed scores with fewer respondents scoring zero (Goodchild, Duncan-Jones 1985). Results using both GHQ and CGHQ methods of scoring were produced in Study 2.

A threshold of 5 was chosen for the GHQ-30, reflecting the modal value of 4/5 for hearing people on 31 validity studies of the GHQ. The mean scores for the GHQ were compared to general population means. The Health and Lifestyle Survey (OHLS, Cox et al 1987 cited in Jenkinson 1994) was selected as an appropriate comparison. A random sample of 6,498 respondents completed the GHQ-30 along with other tests. Results provide an indication of health within an age group similar to the Conrad sub-sample (25-34 years).

Using the traditional GHQ scoring system there was a significant difference between the mean score for respondents in the Health and Lifestyle Survey (4.03) and the mean score for the Conrad sub-sample (7.14). A critical value of $t=2.40$ was obtained which was highly significant at $p<0.02$, $df=1298$. The Conrad sub-sample scored lower on the GHQ-30, suggesting poorer mental health.

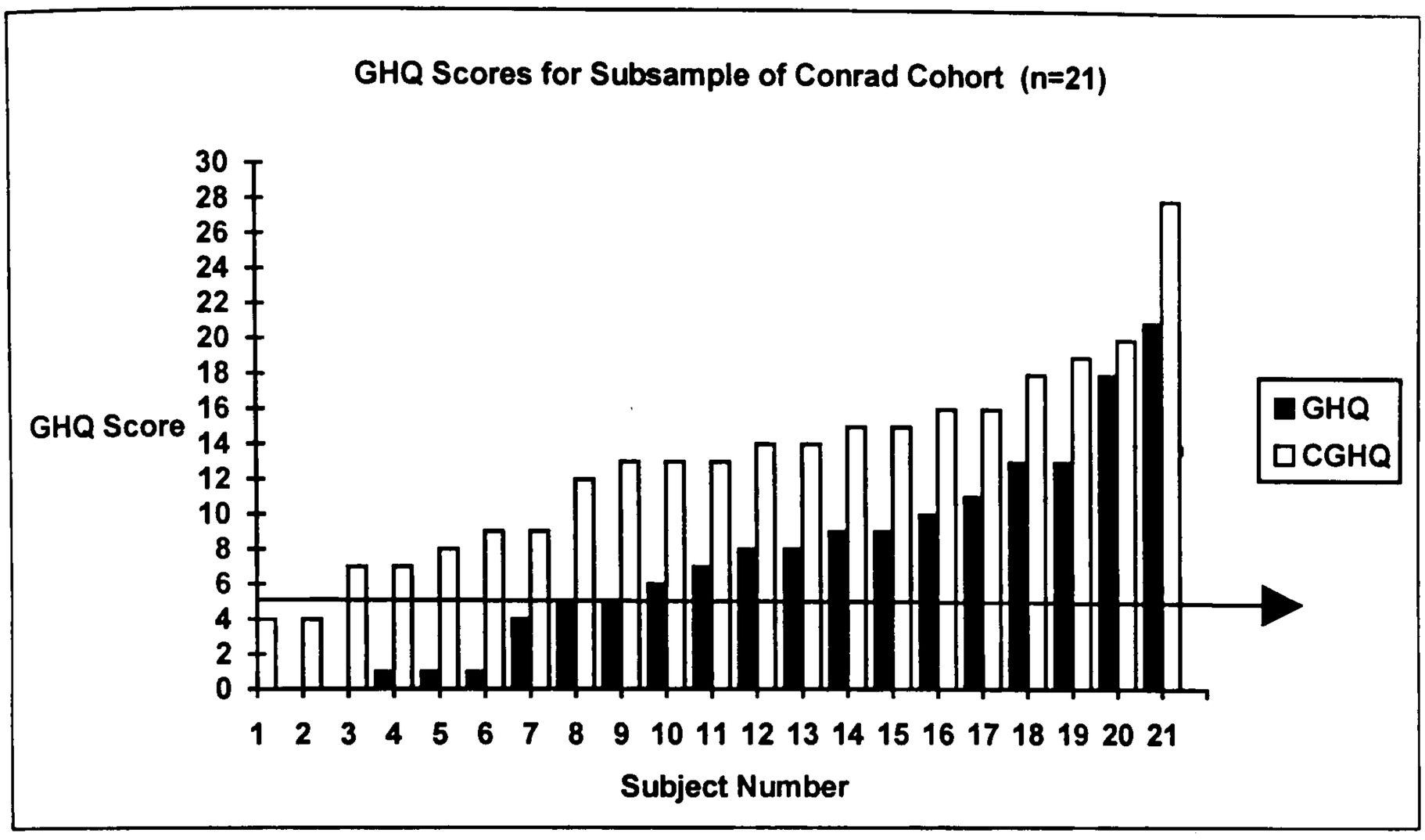

Figure 5.1: Scores for GHQ and CGHQ for Conrad Sub-sample

For the GHQ a threshold is normally established, above which a score indicates 'caseness' in the respondent. The threshold used may vary across studies and populations. The most commonly used threshold for GHQ-30 according to a survey of 31 studies (Goldberg and Williams 1988 p64) is 5 (marked with an arrow on table 5.1). This threshold is also used in 'The Health and Lifestyle Survey' (Cox et al 1988) Following this guideline the number of those in the Conrad sub-sample whose scores were above the threshold, when scored using the traditional GHQ scoring method, was 14 (66.6%) and when using the CGHQ scoring system was 19 (90.5%). In the Health and Lifestyle Survey, a much lower number representing 31% of those interviewed scored above the threshold of 4/5 (using the traditional scoring system).

Checinski (1991) created an adapted version of the GHQ-30 for use with deaf people known as the GHQ(DP)-33. It would be inappropriate to compare directly this adapted scale with results for the sub-sample; however an initial comparison supports the fact that even with an adapted version of the questionnaire deaf people may score significantly higher than the general population. Checinski (1991) assumed a threshold of 5/6, with 37.4% of respondents scoring above the threshold (n=52), and 80.8% diagnosed as cases

upon interview. Using the threshold of 4/5, 43.2% of Checinski's respondents (n=60) scored above the threshold, with 70% turning out to be cases upon interview.

5.4.2 Summary of GHQ-30 Results

In summary the mean scores for those in the sub-sample were significantly higher than an age equivalent hearing sample, the vast majority (90.5%, using CGHQ) scoring higher than the threshold most commonly taken to indicate a likelihood of illness in an individual.

5.4.3 SF-36

All SF-36 questionnaires were completed in full (n=21) and analysis of results produced raw scale scores for eight scales. These were then transformed into 0-100 scale scores for each scale. As with the GHQ, a national survey was selected against which to compare the Conrad sub-sample mean scores. In 1993, 13,042 respondents from four English Health Service Authority's lists (Wright, Harwood, Coulter 1992) were interviewed. This questionnaire will be referred to as the OHLS (Oxford Healthy Lifestyles Survey). From this sample the scores of a comparative sub-sample between the ages of 30 and 34 years was examined (n=1134). A two-tailed t-test determined if there was a statistically significant difference between the mean scores for the Conrad sub-sample and the comparison group.

Table 5.2 displays a summary of scores for the eight SF-36 scales.

Scale	Mean Score OHLS[16]	Conrad Sub-sample Mean	t value	p value <	df	Significant/ Insignificant
Physical Functioning	92.6	82.4	1.94	0.1	1153	Higher but insignificant
Physical Role Functioning	88.5	72.6	1.87	0.1	1153	Higher but insignificant
Pain	83.8	81.3	N/A	N/A	1153	Insignificant difference
General Health	76.3	69.7	1.28	0.2	1153	Higher but insignificant
Vitality	60.3	54	1.86	0.1	1153	Higher but Insignificant
Social Functioning	88.4	71.3	2.36	0.02	1153	Significantly higher
Emotional Role Functioning	82.8	55.4	3.78	0.001	1153	Significantly higher
Mental Health	72.9	63.8	2.34	0.02	1153	Significantly higher

Table 5.2 Summary of results for SF-36 against OHLS mean scores

General Health: results suggests that those in the Conrad sub-sample were more likely than a random population group to believe that their personal health was poor and likely to get worse.

Vitality: mean scores suggest that those in the Conrad sub-sample were more likely to indicate feeling tired and worn down all the time, rather than feeling constantly full of energy although the difference was not significant.

[16]Numbers in brackets refer to transformed scale scores 1-100

Pain: the bodily pain scale refers to the limiting effect of actual body pain. Unsurprisingly the Conrad sub-sample were no more likely to experience debilitating pain than the general population.

Physical Role Functioning : results suggests that the Conrad sub-sample reported more problems (non significant) with work or other daily activities as a result of physical health limitations.

Physical Functioning: results suggest that those in the Conrad sub-sample were slightly, although not significantly more likely to be limited in their performance of physical activities due to ill health.

Social Functioning: results suggests that the Conrad sub-sample was more likely (although not significantly more likely) to experience extreme and frequent interruptions to normal social activities due to physical or emotional problems.

Emotional Role Functioning: there is a highly significant difference between the Conrad sub-sample and general population in the extent to which emotional problems instigate problems at home or work. The deaf sub-sample reported significantly greater disruption in emotional role functioning.

Mental Health: a significantly higher proportion of the Conrad sub-sample reported feelings of nervousness and depression for more of the time than the comparative hearing sample.

5.4.4 Summary of SF-36 Results

Scores for the SF-36 also point to a significantly higher rate of mental ill health within the sub-sample. Between the two populations scores were not significantly different on measures of physical body pain. For measures more closely relating to emotional functioning, mental health and social behaviour, than to organic illness, the difference in scores was highly significant. This pattern echoes the findings of Study 1, in which the incidence of referral for emotional, behavioural and personality disorders within the total

cohort was particularly high, against referrals, for example, for psychotic disorders, the latter often given an organic aetiology.

To summarise, findings from standard measure assessments of health point to alarmingly low levels of mental health within the sub-sample, as measured against hearing norms.

5.5 Introduction to a Qualitative Analysis of Wellness

While standard measure assessments of health reveal a certain amount about the health of those in the sub-sample in relation to population norms, on their own they are limited in their ability to explain such apparent deviation. The aim of Study 2.2 was to allow respondents to discuss health and wellness and factors they considered contributory, using their own frames of reference. The study provided an opportunity to conduct a qualitative analysis of wellness, constituting an exploratory journey into the conceptual world of a group of deaf people.

On analysis, this qualitative data strongly supported interpretation within a systems theory framework. To recap, systems theory (Payne 1997) views the individual as an energy system, which rather like other biological systems, has boundaries across which energy may pass. Systems may be open, thus allowing the interchange of energy, or closed in which case boundaries are impermeable. The goal of the system is to create a state of homeostatasis or equilibrium whereby despite energy change, the individual's fundamental nature remains constant. A state of entropy is one in which systems use their own energy to keep going. Unless the system receives energy from outside the system 'it runs down and dies' (Payne 1997, p138).

Although interviews took place independent of one another, strong patterns emerged across the data. The three most dominant themes will be considered below. Rather than being areas of conceptual convergence or divergence between respondents, the first two thematic areas emerged as continua, with clusters of respondents occupying similar locations. The first conceptual area constituted the often ongoing *emotional* acceptance of deafness; and the second, the styles of individual *coping* with deafness. The third

conceptual area is concerned with the respondent's references to the *dynamic* nature of wellness. Each area will initially be discussed separately. In order to protect their identity, all respondents names have been changed.

5.6 Emotional Acceptance of Deafness

5.6.1 Non-acceptance of deafness: the emotional response

A difference emerged between those able to accept and those unable to accept deafness. Within the sub-group of twenty-one, seven respondents could be described as being unable to accept deafness. This lack of acceptance had two aspects: firstly, references to *suffering*, and secondly a *reluctance* to *identify* with other deaf people or the deaf cultural community.

5.6.1.1 Deafness and suffering

A third of all respondents were clear that in some ways they were victims, isolating factors outside of their control as contributing both to their underachieving and to their unhappiness. They described often feeling depressed, isolated, frustrated, or angry and furthermore perceived irreversibility in the damage done and the impossibility of change.

This can be seen quite clearly for example in education. Three quarters of all respondents harboured resentment at the short term and longer-term effects of unsatisfactory schooling. Teachers were thought to be solely at fault, their attitudes and style of delivering material constituting a barrier to achievement, for example:

> I was disappointed with my education. I wish I'd learnt more, got more GCEs or O levels. I wish they'd encouraged me to go to University. I feel I've been wasted - that there is a gap there that I can't catch up. I think that when I look back, they had no idea who I was (Don).

These beliefs were expressed in different ways. Some had sensed a refusal to accommodate to deafness or "poor teaching, teachers not being bothered" (Mark) or teachers "turning me stupid" (Heather).

Two or three individuals considered all onus to have been upon themselves to compensate for deafness. In the family, for example:

> I used to argue and I guess because I couldn't hear I used to get the wrong end of the stick. They should have been clearer and me maybe, both really. That's life, you have to struggle and try really (Georgina).

While explanations were often found in childhood, the effects on wellness in adult life were still significant:

> I used to feel - how can I say it.. when I was at school it was a hard time, same as it was at college...often I still feel like that with whatever I'm going through. I feel that I'm left out, I'm shut away. And it's quite hurtful. I just want to join in but it feels like you're an alien or from Mars...all the children used to take the mickey and I kept saying 'come on you've got to be strong', but I'm terrible, I'm still weak (Georgina).

While other respondents grew up to accept deafness, approximately one third of respondents felt that the effects of experiencing a lack of control of their lives had continued into adulthood.

5.6.1.2 Identification with hearing people

Those who did not associate with other deaf people expressed reluctance to identify in any cultural sense with other deaf people. Deafness carried only negative connotations:

> I was more or less brought up in the hearing world. I don't have much contact with the deaf community. I forget to tell people that I'm HOH[17], deaf whatever, I hate that word deaf (Maureen).

Within this group, deafness was perceived of solely as a disability. In no sense could deafness be conceived as contributing to an experience of wellness. Avoiding contact with other deaf people confirmed that things were never "quite that bad". The 'Deaf deaf', or those culturally deaf people who used sign language and associated with other deaf people, were actually pitied:

> I don't see Deaf deaf people. My husband feels strongly that the Deaf deaf people make it worse by not letting the hearing in to help them. It's like the Yorkshire/Lancashire rivalry. For the hearing deaf it's easier. Some of the Deaf deaf complain that they

[17]Hard of Hearing

> haven't got jobs. They act like they have blinkers on. The Deaf deaf think they run the world. We do try to help them, hearing people do try if they let us. I'm probably wrong, but hearing deaf get to do more things like paragliding, whereas they might not want to do it as it's a hearing thing, and adventurous things like going abroad on their own. Yes Deaf deaf tend to go around together and tend not to be as adventurous. At school there were a few who were good at sport but I didn't feel they were trying hard enough. I loved sport. I feel sometimes that they thought all hearing people were all bad but that's not right (Caroline).

The Deaf deaf were thought to be in need of help to "add a bit more to life than deafness" (Heather).

> I know a deaf lady, her name is Margaret and she signs. She's been going to speech therapy to get her to speak better. I'm pleased for her. She's trying to cut down on signs. I thought 'why can't I learn that?', I mean I see people walking around and one person looked lost and I saw them doing this (signs) and I thought, 'you poor devil!' I wish I could have helped him and it really frustrated me; I wished I could have helped him with what he was looking for (Georgina).
>
> Probably, it must be worse for them (profoundly deaf). People have to be looking after them (Liz).

While somewhat distorted perceptions were often the result of a limited awareness as to the nature of the deaf community, the strength of feeling among this group suggested other factors at work. Particularly for those most isolated, fears towards their own disability appeared to be projected upon other 'Deaf deaf' people perceived to be in a worse situation. Several respondents spoke as hearing people, sympathising with the 'Deaf deaf' despite having reported being in a very similar situation themselves, for example with regards to employment:

> They do have problems. I think one of the worst areas is job opportunity. They are very restricted. Deaf people do have problems. One deaf person I know has been in the same firm for 15 years. He's very good at what he does but it's low wages and he's trapped. The only area they can't do is telephones. Any Deaf person can type or do office skills. They're in a dreadful position (Sean).

For this group, keeping deafness at a distance helped maintain wellness. This included minimising any effects of deafness and condemning behaviour that consolidated the acceptance of deafness in any form. There was a corresponding lack of tolerance for attitudes or behaviour in others that drew attention to deafness. For example, the use of sign language was something to resort to, only if attempts at lip-reading and speech had

failed. Those able to speak, who opted to communicate in sign language, were either giving deaf people a "bad name", or were lazy.

> I agree with not allowing sign language. Why should people working in the job centre or whatever learn to sign language [*sic*], it's not going to get them anywhere. Speaking should be encouraged and signing discouraged because it makes you seem like the odd one out. I also find that deaf people are extremely selfish. They feel sorry for themselves. Most of my friends are hearing. I have about 3 profoundly deaf friends but they are completely integrated with the hearing world. They won't do sign language when they're with hearing friends, they try their best to lip-read and it's very effective, and so because they are such nice people, hearing people say 'OK then we'll learn to sign'. People with pure sign language make no effort (Sean).

While one or two respondents described feeling fairly stable emotionally, several others were isolated and frustrated and in their denial of deafness constantly confronted situations which challenged their beliefs. The latter group, while reporting fairly strong views of themselves, did not present themselves as a stable system, but rather, fairly threatened. For example, the experience of motherhood heightened differences between themselves and mothers of hearing children:

> My son wasn't very happy for a while and it was because of me. Some of the older ones were teasing him because his mummy talks funny. I was very hurt at the time. My family reassured him but he didn't know any different. I have a lot of supportive people around but they're all normal hearing. It's nice to have those friends but it really gets to me. I wonder if I'm doing things right or if it's my fault (Ruth).
>
> My little boy was talking without his voice. They told me that might have been why he wasn't talking but I hadn't realised. Basically they've learnt to look at me and they do it automatically. It's worrying really (Tim).

The common experience of parenthood appeared to be overshadowed by a sense of difference between themselves and other hearing parents.

5.6.2 Acceptance of deafness: the emotional response

Within the respondent group, two thirds could be described as having heightened awareness of the emotional effect of the whole experience of deafness and had accepted deafness. Their acceptance was of the experience of being deaf in a hearing world. These people were able to respond emotionally to society's barriers to normal life and

wellness rather than believing the inability to hear had had any direct effect on achieving a state of wellness.

For example, respondents who identified themselves as being culturally deaf did experience negative or damaging emotional reactions to stressful situations, but for reasons which differed from those who appeared to reject deafness. The emotional response nevertheless can also be immense:

> I was told at the careers convention that I wouldn't be able to work with deaf people because I was deaf. That's what I really wanted to do. I walked out because I couldn't see how they could tell a deaf person to be a telephonist but not a children's nurse. I applied for lots of jobs but was always told no vacancies. Barclays, Sainsburys all turned me down but were still advertising for more vacancies after. I went for job after job. If I said I was deaf there was no response. When I didn't say I was deaf I got an interview...when they found out I was deaf I was stuck. Tescos thought I might be an embarrassment to customers. They don't ever put it in writing. In one place I was so angry when my sister in law got the job. I had a right go at the manager in front of the other customers, so she invited me for interview and I got the job. I know I could have done those jobs. I wouldn't have applied to be a carpenter because I couldn't put two bits of wood together! I was being nice and it was getting me nowhere. Deafness has definitely been a block. (Caroline).

Being denied access to information or receiving different treatment provoked unwelcome feelings of inferiority. As the example below illustrates such reactions were based on an awareness of their equal rights as deaf people:

> I feel really frustrated with the social worker- they're still much too powerful. Because of them before I didn't know what I'm actually entitled to as a deaf person in terms of interpreting services and so on. I usually use my mother but it made me mad - I didn't realise I was entitled to things like antenatal classes and so I wasn't involved in anything like that before the birth of my first child. I had very little idea about feeding etc. all because of lack of access to information (Sarah).

Anger rather than isolation typifies the response to accusations that deafness interfered with respondent's roles, for example, as a parent:

> My (hearing) son had behavioural problems at school. When they found out, the teachers immediately assumed it was related to his parent's deafness which made me really angry. I told them so. It was rubbish! (Sarah).

Many of those who displayed a positive acceptance of deafness as adults had very different experiences earlier in their lives. Recollection of childhood for many

respondents, particularly from hearing families, involved admitting to experiences of extreme frustration, most often as a result of impoverished access to information. Several respondents recounted being ordered to "sit quietly" or watch TV while other hearing members of the family talked together.

A high percentage of those interviewed claimed that they had been unable to communicate with their family. Of those who went to residential boarding schools, several described looking forward to the end of weekends or holidays at home as the return to school symbolised the return to communication.

While recollecting very difficult experiences as children, their explanations for exclusion, unlike respondents who did not accept deafness, tended not to focus on their own failing but rather on causes beyond their control. Following a systems theory approach they recognised that as children they had been overpowered and had had little control over their system or environment. This recognition created a distance between childhood experiences and the autonomy associated with adulthood. For example Heather believed that her mother was highly reluctant to accept her daughter's deafness:

> You wouldn't think my mother had a deaf child. She would always talk with her hand in front of her mouth and my father would always point it out to her (Heather).

In retrospect the behaviour was described as unfair but was recounted with amusement in view of the fact that as an adult such treatment from others would now not be tolerated.

Others explained behaviour that excluded them as an inevitable attempt by the family to normalise the situation:

> My dad never understood me...I didn't understand him but I'd look at my mum and she'd explain. He still forgets I'm deaf. Although I went to a wedding recently and even mum whispered something in my ear! She'd forgotten that I was deaf.. I felt good because it meant at last I was being treated normally (Caroline).

In both cases above, a distance had been achieved between childhood and adulthood that had allowed the respondent to gain control, in this case rendering deafness acceptable.

Some respondents, who as adults had acquired a positive attitude towards being deaf, nevertheless expressed anger or blame towards their families. They were clear that although they were no longer children the long-term emotional trauma of childhood was felt into adulthood:

> My mother signs and I'm really close to her. When I was growing up I never saw deaf adults at all. I have such sad memories of childhood. I relied very much on my mother and I felt I had no connection with my father. I was left out of family social events and I remember spending a lot of time in my room playing with my toys (Sarah).

Similarly moving accounts were given of experiences at school which explore both the emotional response at the time which for one person was actually suicidal and for another extreme depression, and the longer term effects on emotional state. Again, in the quotation below, school is blamed for not looking after the child:

> My parents had no experience of deaf children and didn't know what to expect so they (school) had a responsibility to look after us and prepare us?! But instead it was the best day of my life when I left...two minutes before my dad arrived they told me I could leave, even though they'd known a long time before, and it was such a relief (Caroline).

5.6.3 Summary

Respondents had reached adulthood and had either accepted or rejected deafness. In both groups, wellness was often shaped by earlier experiences. In the former group were those who appeared to struggle in their attempts to be accepted as normal or akin to their hearing peers. Respondents reported feeling not only that they had little control over their lives, but also that they had actually been damaged through the behaviour of others. Unsurprisingly there was a consequent reluctance either to see deafness in a positive light or to identify, in any positive way, with culturally deaf people.

The experience of those in the latter group, as one might predict, was less confrontational. Their acceptance of deafness had not removed wider society's prejudice. However, they had found an effective means of coping. They had transformed their lives from existing within a system in which others exerted control, to sustaining a system based on autonomy and choice. The ability to cope was often exhibited in asserting their rights to

equal treatment. The ability to demand equal treatment, in turn, was based on the conviction that deafness did not affect their ability in any way.

The following section will explore respondent's accounts of their coping strategies.

5.7 Coping Strategies

The majority of those interviewed described experiencing stress on an everyday level through living and working in hearing orientated society, where often mundane activities became obstacles because of hearing loss.

Systems theory presents the individual as a system in a state of homeostasis and a relatively stable equilibrium exists between positive and negative interdependent influences. A positive steady state is one that is able to admit change and yet maintain stability. At times, the system is unbalanced and the individual, quite simply, cannot cope. At this point, the individual may struggle to sustain wellness processes.

At other times the system maintains stability but the underlying dynamics serve to prevent rather than promote wellness. This may be due to long term oppressive treatment by others or because the individual has accepted a subservient status.

The following section will consider the existence and evolution of coping strategies, by which is meant the often behavioural, often emotional habits which constitute the maintenance of a system.

As with section 5.6 a consideration of styles of coping will be presented in two extreme forms, 'negative coping' and 'positive coping'. Again respondents were located in clusters between each extreme. Issues of adjustment were faced by all respondents. While categories of positive or negative coping were not expected to be clear cut, within an ethnographic analysis, judgements were made in the interpretation of finding.

5.7.1 Negative coping

Respondents were asked how well they felt they coped with deafness. That is, they were probed as to the strategies and resources, practical and emotional, with which they encountered deafness. Negative coping emerged as being characterised by both 'inactive' strategies and 'active' strategies. While the former often involved shutting down areas of life and assuming a submissive or protected stance, there was evidence of many active strategies. Taking responsibility for concealing deafness and attempting to accommodate deafness, often at the expense of achieving identified goals, represent some of the active strategies employed.

5.7.1.1 Inactive strategies

The following section will consider some of the inactive strategies employed within the area of negative coping, for example, adopting a disabled stance in which respondents reported characteristically submissive roles in relation to family, friends or at work. This was often based on low self-image and expectation and commonly represented a continuation of roles established in childhood. Coping strategies often centred on the acceptance of the least disruptive state.

Approximately one third of the respondent group did not feel they were able to cope particularly well. As with the acceptance of deafness, it became clear that many of those interviewed considered themselves disabled by deafness or "like an incomplete hearing person" (Maureen). Respondents in this situation were impotent to effect change, and accepted without dispute ceilings placed by others on their expectations and ability:

> I didn't bother with qualifications, X (teacher) looked after me at school...he got me the job when I was in school. I don't think I'm clever enough for qualifications. The head said I couldn't go any further after what I'd gone through. I've got a good home, a good husband, two children, I'm a good cook but I couldn't go any further with my brain (Ruth).

Unsurprisingly in most areas of life this group of respondents had themselves defined limits or system boundaries, for example, in work, socially, or within the family.

Corresponding coping strategies were passive often characterised by acceptance of sometimes uncomfortable situations:

> If the other mothers come round for coffee they talk to each other but I don't know what they're saying and I get fed up with it. A lot of my friends are like that and I don't know what they're saying. I'm not happy not being able to talk to people in the pubs and that though. They don't ignore, me they include me but it can be hard. They could make more effort. When a bloke comes up to me and asks me to dance I can't hear what he's saying and it makes me angry inside. I was at Oscars [club] and this bloke asked me to dance, well I presume he did, and he kept pestering me. I told him to go away. I presume he said that. They're all horrible looking. He came up again and he didn't get the hint. I was left on my own, as my friends were dancing. I couldn't get rid of him, it was horrible. When I can talk to them outside it's different. I tried to join a dating agency but it costs eighty pounds to join and I can't really afford it. I'm too scared to do it. I don't know if it's because of my deafness or not. Should I put down that I'm deaf? (Liz).

In other situations, the least disruptive option was to limit domains of activity, for example, to the immediate family:

> We try twice a year, once for Mike's (husband's) Christmas meal and once for our anniversary but we haven't been out for a couple of years. There's a bingo near here. I used to go every fortnight. I go with my sister-in-law but other than that because of being deaf I don't really have friends. I know other parents through the school but I don't go out with them. I pop round for coffee in the day maybe, but I haven't done that for ages, it's always a bit strained (Caroline).

The net result was that in many cases respondents' environments while displaying both predictability and stability were in a state of entropy. That is, as a system, they were relatively closed and they relied predominantly on their own strategies and their own energy. Much of their behaviour, described here as negative coping, necessitated shutting down various domains of their life in order to minimise encountering situations perceived to be threatening.

The area of work emerged as one in which inactive strategies were particularly obvious. Respondents' accounts of work focused broadly on two areas, the strategies each employed to obtain work and the subsequent negotiation of deafness in the work place.

Eight of the sample were employed in unskilled manual work. Of the remaining five, four were housewives and one person was looking for work.

Of those who described themselves as housewives, two respondents appeared content with the situation, safe in the knowledge that their partners were able to support the family financially. Two women firmly believed that their (partial) deafness prevented work of any kind. As Sandra explains:

> My mum didn't tell me what to do. So I went to college but no job, nothing. I didn't know what to do, my mum didn't tell me about work, I didn't know what to do about work. I spent 5 years on the dole not working. I went to College and had to stay away from home. I was 20. I loved it, I wanted to go back but... I want to learn something, to be a bookkeeper. You have to do it for 8 months then you find a job, but not if you're deaf, right? My husband has a computer upstairs so he wants me to do work upstairs. I don't know what I want to do (Sandra).

Three respondents were reliant on their family to find work for them. As with other areas of their life, they believed themselves incapable of making autonomous decisions. Work obtained in this way was typically manual and low paid:

> I left school at 16 and tried to find work...one month and no work. Mother tried to find work for me, she found me a job in a printers and I stayed there for 3 years. The pay was very low. I was cleaning and polishing rollers. I was the only deaf person there. I moved to B and started to work there; it was good work and I stayed there about 14 years, working in a press. I was the only deaf person again. I've never worked with other deaf people. Mother found another job advertised in the paper at Tescos so I got a job there in the warehouse (Peter).

Deafness was considered an impenetrable barrier and consequently low self-expectations developed into attitudes that were characteristically compliant. In terms of coping, to varying degrees, this group of respondents coped either by internalising the low expectations their families had of them, or as the example below illustrates, by having low self-expectations:

> I worked hard and I was promoted four years ago. I wasn't expecting to be promoted. I just left school and wanted to see if I could hold down a job because of my deafness. I was petrified everyday going into work for the first two or three weeks. I felt that I could fail really easily but I wanted to go in and be successful. (Stewart).

When Tim was asked whether it was the shortage of jobs or his deafness that had stopped him from being promoted, he replied:

> Both, I mean deafness does come into it. I feel a lot of discrimination, I mean they need to cut down on staff. I am good enough but I need a little bit more. I need more training. I'm a burden! (Tim).

Once in work respondents differed dramatically in the style in which they approached the work situation. Those typically in unskilled manual work demonstrated few skills with which to cope with being deaf in a predominantly hearing environment. Peter, for example, spent much of his working day without communicating with other people. His response constituted a further example of limiting the perceived environment. When asked how he would communicate, should he want to, he claimed that his workmates all understood and used sign language but that he chose not to communicate with them. There is a strong suggestion that rather than being strictly true, this is how Peter has chosen to perceive, or at least report his work environment.

Similarly in the area of family life one respondent's experience was typical of many who submitted to situations perceived as threatening. Heather's husband had put pressure on her to mix with "normal" people rather than with other deaf people. His frustration with her deafness was expressed through challenging her use of the telephone:

> My husband gets me really worked up. He'll say 'You go to the phone, you phone them up!' and I say 'I can't hear what they say', I just don't understand them. I don't know, I mean maybe he forgets. I tell him I really can't hear what they're saying and I ask him to take over from me and he won't do that and he just sits there and I get into such a state that I can't hear! The more I concentrate the worse it gets but I can't do anything else (Heather).

While some respondents were able to identify areas of dissatisfaction in the immediate environment, there were some longer-term concerns expressed. For example, several respondents were concerned that they had not achieved some of the significant milestones of adulthood such as meeting a partner or pursuing a career:

> I don't think I'll ever get a full time job because of my disability. I know what I can and can't do, I'm in between I suppose, not deaf or hearing - it's just the way it is (Liz).

For many, particularly those who had no contact with other deaf people, a certain continuity had again developed between childhood and adult life. Those who displayed limited coping strategies were least likely to adapt to changing demands and expectations,

and as a result preserved types of relationships and behaviour associated with being a child. Ruth, for example, had been protected by her mother, and latterly, her husband had taken over where her mother had left off in protecting her and ensuring she didn't have to "get in" with other deaf people. Her method of coping was to accept that she would always need to be looked after:

> He's done an awful lot for me, he's helped me in many ways; he doesn't say much but he has. I could have ended up mixing with the deaf but then I met X and he took over. He was my only boyfriend and we've been married 17 years in April (Ruth).

In a similar style, Georgina described her mother's continued responsibility not only as primary communicator between Georgina and the family but for taking care that her daughter finds work:

> My father doesn't sign, only speaks. I can't lip-read my father, so I never communicated with him. Mother can sign a little bit. I can lip-read her better, my sister's the same as mother. My father, I don't know what he says. My mother talks to me, tells me things like finding me a job. She arranges for me to go out with friends (Georgina).

While it would be logical to identify stability in the maintenance of this protected state, the lack of satisfaction in respondent's testimonies would prevent such negative coping being described as a state of wellness, as Sandra's experience supports:

> I think my mum knows everything. I can't remember what I felt like. I didn't like hearing aids. The woman didn't tell me anything. I didn't know anything. Something like that. My mum doesn't talk much to me. Doesn't tell me what to do enough. At the time I didn't understand about work, she didn't tell me. I just got fed up. At 21 I'd had enough. Then I got married when I was 21. I wanted some more, a good job, some friends. Mum and dad kept treating me like a kid. I'm happy now. My mum wanted me to go back there after having children but I'd had enough. My mum is still worried about me (Sandra).

An examination of an apparently inactive process reveals certain contradictions. The group of respondents whose behaviour was apparently inactive nevertheless imposed certain limits and boundaries on domains of their life in order to create a sense of predictability and safety. The placing of boundaries while ultimately preventing activity in these areas required, for their construction, an active process. At the same time reports, for example, of methods of obtaining work revealed the same respondents to be unlikely

to make many autonmous decisions; and ultimately to be in an inactive and somewhat risky state. This apparent contradiction can be explained if the imposing of limits on the world is viewed as submission rather than a more active process.

The following section examines references to negative coping strategies which are more active in nature.

5.7.1.2 Active strategies

In the homeostatic model of wellness, a situation of negative coping results from activity as well as the inactivity described above. Broadly active strategies include expending large amounts of energy in proving capability "despite being disabled". This strategy results from taking responsibility for compensating for deafness and often has as a goal, the concealing of deafness.

Many of the respondents with hearing families reported various strategies employed on a daily basis to minimise the consequences of deafness. For example, family meals for one person were reluctantly abandoned in order to have mealtimes alone with her partner. She had found it impossible to lip-read conversations otherwise, and all previous attempts to remind her family to accommodate, had been futile.

This scenario was typical particularly within the families of those with partial hearing loss. Coping strategies emerged in response to the onus being firmly placed with the respondent to change, and to prove their ability to cope. In effect responsibility lay with the deaf person for minimising the effects of deafness. In three such cases the family had demanded active coping. Clearly there are implications for emotional wellbeing. These three respondents reported feeling at their lowest when faced with situations in which they felt unable to compensate for deafness.

For almost half of those interviewed, everyday coping with deafness entailed often quite elaborate practices which sought to conceal or minimise the disability. In the workplace, for example, deafness was presented as a source of amusement to work mates, as was switching off their hearing aid, as Sean describes:

> With a lot of people I do find it a bit hard. I'm a bit antisocial at work. I take my hearing aid out and just see it as cutting off other interruptions (Sean).

For several people this evoked memories of strategies developed to cope with having limited awareness of activities in the classroom, such as copying other people's work or developing a nodding response. Tim identifies what he describes as "hearingisms" developed during school days which now enable him to disguise a lack of understanding at work:

> I have problems with English sometimes which is a problem because of my job. At school we learnt certain 'hearingisms' such as 'oh really!' and that helps. At the moment I have a deaf friend in the bank and we help each other with hearingisms (Tim).

One or two individuals displayed characteristics of coping which lay between positive and negative coping. They displayed very powerful drives to prove capability based on, for example, using deafness to obtain work and yet rejecting deafness as part of identity. Sean was highly critical of culturally deaf people whose behaviour excluded others, nevertheless he had created extremely active and elaborate strategies both to obtain work and to negotiate deafness within the workplace:

> Then I got into garage trade. The manager said I couldn't work there because I couldn't do the forecourt work. I begged him to give me a week. After the first day he kept me on because I broke all records for one day's work. I stayed there for 2 years. Then another place heard about me and took me on but I had to start off washing cleaning and polishing the cars because they weren't sure with me being deaf. I progressed to being in charge of PDI department for new and used cars. I sold more cars than my sales director did! I talked about my deafness because I didn't know enough about cars. Eventually I was earning so much money I had a brand new car every six months (Sean).

As the following section explores, for others, a homeostatic state is built upon coping strategies that confirm deafness.

5.7.2 Positive coping

Two thirds of respondents displayed positive coping strategies, that is, their emotional and practical response to deafness was based upon accepting deafness as part of their identity. This did not mean that they were all members of the culturally deaf community,

but rather that they had internalised deafness to the point at which barriers to achieving their aims were located in the environment rather than within themselves.

The following section will consider the processes involved, considering firstly those operating on an individual level and secondly, in the context of a social network.

As might be predicted, all but two of the nine people with profound hearing loss were in regular contact with other culturally deaf people, if not active members of the deaf community. All seven were living with deaf partners at the time of interview and of the remaining two, one person was single and the other divorced from a hearing partner. Five of the nine in this group had at least one deaf child while the remaining four were parents of hearing children.

Of the twelve respondents with partial hearing loss, nine were with hearing partners although one person had divorced; one person was single and two were living with deaf partners. Of the latter, both had maintained contact with the deaf community either because they were raised in a deaf family or through sustained contact with deaf school friends; and all those in the partial hearing loss group were parents of hearing children.

5.7.2.1 Individual coping

As one might expect, those who had developed coping strategies based on positive self-image were in successful white collar jobs, many in highly qualified positions. This accounted for eight of the respondent group of 21. The domain of work exemplified the attitudes of this group.

In the workplace high achievers typically insisted upon special provision as an access right. For example, one person had insisted upon a sign language interpreter for group meetings. Another respondent was concerned that having no access to conversation outside meetings was putting her at a professional disadvantage:

> Some people think that because of the hearing aids I can hear normally but that's not the case. As soon as there are two people I get lost. I explain, even to my boss, but it's difficult. I interrupt but people aren't always patient and they've never had a deaf person

> before. Most are patient people, but it's hard to explain it. If the opportunity was right I could. I get frustrated. I explained to one boss that people talk in the corridor about work, and I insisted to the boss that I wanted to be aware. I'm always the last person to know. So he sent a memo telling people to be aware that if they talk to people they should let me know (Rachel).

In an era in which technology has eliminated many barriers formerly associated with the inability to hear, many were able to insist upon technical communication aids as a practical strategy to negotiate the workplace:

> When they use TV and video, I bring in my own infra-red headphones. Every so often the partner would use the video but they'd always wait until I'd switched back on to microphone. They were very good. When I first came they had no idea and there were problems. One of the ladies called after me and complained that I was ignoring her, but she didn't know. They've been made aware now (Jim).

These respondents were then in a position to identify and search out situations which promoted equality, and were in a more confident position to object to those which they felt did not. For this group, wellness, in turn was inextricably linked to equality and equal access:

> I can cope with practical things, like having a house and so on but I can't always cope with other problems. It helps having things like BDA videos explaining benefits and so on, as a lot of problems are based on not having access to information. I don't have contact with the SWD[18] who can't sign anyway- I don't want or need anything from them. I turned him away when he arrived with someone to fix environmental aids to house. We need more generic social workers who are just aware of the situation with Deaf people or interpreters who can eliminate communication problems (Paul).

Accepting a deaf identity clearly did not involve living or working entirely apart from hearing people. While one or two respondents in the sub-sample insisted on working only with other deaf people there were several who were immersed in what might be described as hearing professional culture. A state of contentment was achieved by pitching individual strengths, often contingent on a positive identity, against challenging working environments. Jim, for example, a successful white collar professional discussed his work in terms of compensation, contrasting his working environment in which much effort was expended on a daily basis in encouraging colleagues to engage with deafness, with his behaviour outside work which more simply confirmed a deaf identity:

> I have friends within the deaf club. We really don't mix socially with hearing people very much. My wife goes to local Baptist church regularly and we know people there but not on a personal level. Most friends I've met through the deaf club. I was in the deaf club all the time at school. I'm much more comfortable around deaf people. My (deaf) wife doesn't mind mixing more with hearing people maybe from the ante-natal group or whatever but I prefer to be with people connected with the deaf (Jim).

5.7.2.2 Coping in the context of a social network

Across the group one striking pattern emerged. Those who maintained contact with other deaf people, unlike those who did not mix with other deaf people, had much in common with one another. Correspondingly, the energy expended in maintaining their system was often focussed on this positive association with other deaf people. Nine out of twenty-one respondents who identified with other deaf people displayed a similar emotional response to deafness, which was one of positive acceptance, and they consequently developed similar positive coping strategies.

Coping strategies based on a positive deaf identity were not exclusive to those who were culturally affiliated to the signing deaf community. Many of those who had succeeded in white collar positions were not sign language users and had relied on the emotional support of other oral deaf people.

Those who described themselves as members of a deaf community, particularly those in professional positions, confidently challenged the extent to which deafness was an obstacle. This confidence appeared to be based on the existence of social support, most often outside work, and on acquired strategies with which to accommodate the effects of being deaf in the workplace. The latter included strategies to combat the internal emotional effects on the individual, which had implications for mental health, and strategies to confront issues of a more practical nature, most often relating to communication. Evidence of each area of coping will be discussed in turn.

Frances describes her relationship with deaf people as emotional fuel for the less easy encounters both at work and in social situations with hearing people:

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[18]Social Worker for the Deaf

> More comfortable with deaf friends? Yes, you don't have to think about making conversation; we understand each other's situations perfectly and there's a lot of support there beyond just easy communication. Like I go to a running club, I don't hear anything. Some remember to look at me and tell me what to do, but people at work, not really. It's hard work lip-reading, in the pub or in the dark (Frances).

Affiliation with other deaf people clearly provided emotional sustenance and a sense of identity often lacking in the workplace. Most of those who were satisfied with working life and who felt they were in a position to fulfil their personal ambitions described a social support network outside work within which they could switch off and feel equal and accepted. As an active member of the local deaf community Mark's social life was protected and was with deaf people rather than work mates:

> Yes, two deaf people worked with me but they left after a year. I don't mind being the only deaf person because I can communicate OK, through their actions and lip-reading, but I don't have a strong link with the hearing, I just meet up at lunch time that's all, I don't go out socially with them. My wife is deaf you see and I go to the deaf club every week- all my friends sign (Mark).

For Don, deep relationships were only possible with deaf people:

> I go out socially with hearing people very little, only those I know very well and I can communicate easily with. With hearing people, it's not more than polite conversation. With the deaf it's much deeper - I can feel happy with them (Don).

Although the type of cultural affiliation varied, networks with other deaf people often began at school and in adulthood continued to provide a network of friendship and support. Maintaining contact with old school friends and with the local deaf community, despite the increasing demands of family life, was consequently both a natural progression and a priority. Over the lifespan, changing patterns of family life necessitated a different style of interaction, nevertheless, this was accommodated in order to sustain an appropriate social network, as Sarah explains:

> Before I was married I used to be very much involved with friends at the deaf club, going out drinking with them or travelling and meeting other deaf people, and through sport, like football or darts. I lived for social things and I was able to forget about work with those friends. Now I can still contact friends with the minicom or face to face at the deaf club, but it is always other deaf people. I've had hearing friends but I can't keep up long term friendships with hearing people. When the children were younger I used to write letters regularly to one deaf friend when I couldn't see her (Sarah).

A consideration of the more practical aspects of coping reveals an interesting pattern. Recognising and accepting a deaf identity, as has been considered on an individual level. was often built upon an insistence upon equal access particularly in the workplace. Interviews with those who belonged to a deaf social network did not reveal elaborate tricks or strategies with which to confront or eliminate barriers in hearing society. Rather, belonging to a deaf community and enjoying a sense of well-being were dependent on two practical aspects of coping.

The first was the recognition that without good communication the individual would remain unhappy and isolated. Not surprisingly the social network was therefore characterised by good channels of communication. For some people within this group, language and deaf awareness rather than deafness itself were the crucial qualities in friendship. Hearing people who could sign, albeit to a secondary degree therefore constituted part of their social network, as the examples below illustrate:

> My friends are more deaf than hearing. My partner at the moment is partially deaf, but friends are a mixture. Hearing friends are usually people who can sign themselves. When we go out socially, I mean it depends where we go, like if it's for a drink it's usually with deaf friends. If it's for a sports group, then it's a mixture of both (Rachel).

> I'm most comfortable with deaf people signing or hearing signing, or people who talk clearly without covering their mouth. Some people can't believe it when they meet a deaf person who can talk - they thought that deaf people can't talk. I tell them they can. I cope with both worlds but only if communication is there (Tim).

The second practical aspect of coping relates to the properties of the deaf community. In this sub-sample, deriving any benefits or energy from the deaf community depended on a recognition that the deaf community was constant, albeit in different locations, and that in order to draw on the community it should always take priority. Despite changes in location or time, for those who were members the deaf community, access was available to a cultural belief system, as Don describes:

> I don't mind socialising with the hearing lot, I mean it's not the same but I do enjoy it, we can go out to the pub and play football and so on...all of my closest friends are deaf...at the pub, the deaf club, at the BDA events, and we think the same way. Hearing friends? Very small number. I'm not in touch with deaf people that I worked with for example in London, but then that's deaf culture - as soon as you meet again all that goes. Most

> friends I've made in the last few years, they've been new friends. I suppose I've lost touch with some of the family but that's partly because of having a new family with all the responsibilities attached and when you've gone through the relatives you have to keep in touch with then the next priority is the deaf community (Don).

In summary, coping strategies, whether individual or developed in response to a social network served to sustain a system; equilibrium or homeostasis was the goal in the individual's lifestyle and behaviour.

Coping strategies, rather than constituting a set of acquired and standardised tools were developed in various forms. In some circumstances, they could be described as negative, in that they perpetuated a system that did not appear to benefit the individual. In these situations, a state of entropy often prevails in which the relatively closed system is sustained by its own energy. Without inputs from the outside a state of entropy can often lead to the system collapsing in some form.

In other situations, coping strategies could be described as positive, in that individuals had established a lifestyle that enabled them to recognise and seek out wellness. The latter group was more open to the possibility of change. As the following section illustrates, the life system they maintained was essentially more dynamic.

5.8 Wellness as a dynamic

Most respondents were eager to talk about their childhood and formative years. For approximately one third of the respondent group, these memories closely resembled their experiences as adults. Often desperate accounts of feeling isolated and helpless were repetitions, in adult form, of experiences in childhood. Particularly among those who maintained little, if any, contact with other deaf people and who described being disabled by deafness, there was little identification with notions of change and transition. Both in retrospect and in response to enquiries about the future, there was little experience of change or expectation of it. Expressions that suggested learned helplessness precluded any insight into the possibility of change. Correspondingly, in each case their experience of wellness appeared to be relatively static.

In contrast, approximately one third of respondents described the transition, of choosing to move from situations that did not promote wellness, to those that did. Consequently, a strong relationship emerged between wellness and having made this transition.

In some situations an increased sense of control and of redressing power inequalities was helped by the evolution of practical communication aids such as Typetalk or the minicom. Others insisted upon the use of sign language, signifying a break from traditionally oral family environments.

For most respondents, a transition in lifestyle went beyond the introduction of practical gadgets or using a different language. Their adult lives had been marked by a cultural shift towards a deaf community:

> Yes, my family never signed. I felt like a stranger in a new country. When I go to deaf club and talk about deaf culture or whatever, it's good. For a long time I didn't want to get involved but now it's great...a friend introduced me to one club...it's a deaf club with more conversation. We talk about history and education and so on. It's easy and relaxed. I started going when I was 19. We get all kinds of TV to tell us what's going on over the weekend. That's a good thing and I'm sure I would have liked to have that when I was younger. It's for people under 30. I'm glad I didn't go to deaf club earlier. I had to see grandparents over the weekend. Also I think my parents wanted me to talk to hearing people (Tim).

Such change is exemplified in descriptions of work. Of the group of those employed in manual work, four described their career path in terms of transition and now looked back on their early working lives as a time of unhappiness. Typically this was from being isolated within a hearing working environment, to working with other deaf people.

> I tried social work for 6 years but only worked with hearing people. I couldn't hear if people were behind my back. Mornings, when I was wide awake, I was fine but later in the afternoon or in group situations, it was awful. I didn't want to make them feel odd, so at that time I thought that I had to make an effort if I wanted to remain friends with them. In a group of about 10 people, 2 would make the effort, the others wouldn't. I had to leave, it was too much. I was redundant for a while, but happy. I've been working for X (deaf organisation) all this time doing freelance work, communication skills courses etc. and working with different groups of deaf people (Marilyn).

One respondent described the relief in finally recognising that certain working environments were conducive to wellness, and others were actually damaging, emotionally:

> I felt very lonely and isolated, I was unable to communicate. I regularly spent coffee and lunch breaks alone. The only communication from others working there was in the form of teasing about small things, which made things worse. I used to miss a lot of work claiming to be sick etc. I only once went to a work social event and was totally excluded, so never went again. I worked there for 5 years unhappily but now I'm working as sign language communication adviser and I love it! (Sarah).

The dynamic nature of wellness is represented not only by a single transition in cultural affinity, but as we have seen throughout this chapter, in the constant adaptations to the individual system in all domains of life. Those who felt they had a good quality of life and were able to identify and pursue wellness maintained lifestyle systems that were open to change.

5.9 Summary of Qualitative Findings

A qualitative analysis of wellness and it's meaning to a sub-sample of the Conrad Cohort revealed two conceptual states. They were, firstly the emotional response to deafness and secondly the existence of coping strategies. Clusters of respondents could be located within each state and as one might imagine, those who described non-acceptance of deafness often displayed limited means with which to search out wellness. Similarly those who had accepted deafness and particularly those who were members of a deaf community, despite often feeling frustrated had developed the means to cope.

It is clear that although a respondent's life system displayed a certain stability, it would be unwise to necessarily equate stability with a state of health or wellness. Those whose testimonies suggested a positive experience of wellness were open to change and indeed sought out that change.

5.10 The Relationship between Quantitative and Qualitative Findings

The aims of Study 2 were to explore mental health within the Conrad Cohort using two different frameworks, one which was essentially quantitative, and norm based, and the

other, qualitative, employing ethnographic strategies which presume no dominant ideology of mental health. The analysis of Study 2 has sought indicators or trends in a relatively random sub-sample, rather than tracing individual scores. For this reason qualitative data has not been correlated with quantitative.

However, it is possible to make an initial comparison, and such findings, presented below, strongly support the notion that standardised assessment procedures may not reveal an accurate or complete mental health profile with deaf populations, and that other frameworks of analysis offer complementary data. While the eight scaled scores of the SF-36 make even a rudimentary comparison to qualitative findings, difficult, the single score for the GHQ-30 allows this.

Table 5.3 summarises the numbers of respondents who scored above or below the threshold of 5 on the GHQ-30, separating those who were judged to be positive copers, who accepted deafness, from those who were judged not to have accepted deafness and who tended to cope in a negative style.

Total	Positive coping	Negative coping
GHQ score over 5	n = 7	n = 8
GHQ score under 5	n = 4	n = 2

Table 5.3 GHQ-30 scores against coping skills - Study 2 (numbers in each group)

While the number of respondents who scored under 5 for the GHQ - 30 (indicating relatively good mental health) was small, more individuals in this group appeared to have developed positive coping (n = 4) than negative (n=2).

Perhaps more significantly, within the larger group of those who were rated by quantitative methods more likely to be ill, a significant proportion (n = 7, almost half) displayed positive coping strategies. That is, although they reported symptoms of behaviour normally associated with mental illness, they themselves reported wellness behaviour, characterised by positive coping.

5.11 Conclusions

In conclusion, results from quantitative evaluations of wellness within a sub-sample of the Conrad cohort would lead us to believe that the deaf state of mental health is poor. The results of quantitative measures of health point to alarmingly high incidence of caseness. The suggestion is that although not referred to psychiatric services for problems of mental health, the existence of problems particularly in the areas of social functioning, adjustment and mental health, is greater than for hearing people.

Findings from qualitative interviews in some ways support a state of ill health within the Conrad cohort and in other ways illuminate different points. It is clear that some individuals have reached adulthood ill-equipped to cope with an independent working or social life either with deaf or hearing peers. It is also evident that almost half of those interviewed are coping well and have identified strategies and resources with which to

pursue wellness. That is not to say that life is always easy for them. Many respondents react emotionally to their state of exclusion in society and aspects of this experience are highlighted in standardised measures of health.

It is appropriate here to first reiterate concerns about the suitability both of standardised diagnostic strategies and of many standardised assessment instruments for use with deaf people (e.g. Lane 1992, and see section 2.6.1). Cross cultural translation of instruments has been somewhat superficial, often limited to the translation of assessment materials and information into sign language. The Conrad sub-sample scores for the GHQ-30 and the SF-36 (both demonstrating acceptable levels of sensitivity to cross cultural situations) pointed to a low level of mental health within the group.

The picture of straightforward ill health was not confirmed in the qualitative data, where the many respondents who scored poorly, when interviewed reported remarkably 'adjustive' strategies. Within the deaf wellness framework, indicators of adjustment are recognised over maladjustment. Responses to stress are framed as activities that lead to an adjustive response. Throughout Study 2, respondents reported on stressful situations associated with deafness. For example, when asked if respondents had been 'finding life a struggle all the time?' (GHQ-30 Question 26), one person who had recently moved house described finding life a struggle 'much more than usual', as a result of getting to know hearing neighbours unfamiliar with deaf people. When confronted with local people she struggled to lip-read, however, the respondent described how she managed to cope with the situation. She prioritised visiting deaf friends at least three times a week, and balanced periods of intense frustration with more 'real' encounters with deaf friends who used sign language. In this way, bouts of stress were quickly and regularly dissolved.

The picture emerging of mental health and wellness in some ways supports, and in other ways contradicts, the idea of a straightforward shift in the norms associated with health. That is, although subjects scored low on quantitative measures, particularly of mental health, their beliefs and perceptions revealed more intricate patterns and perceptions.

Chapters 6 and 7 will explore this idea in a framework of deaf wellness.

Chapter 6 Perceptions of Wellness within Deaf Culture

6.1 Introduction

Exploring the concept of wellness, particularly among the deaf professional group, led to claims that wellness for deaf people could not exist as long as deaf people were oppressed:

> I mean what does wellness mean, that you feel OK and that you are happy with your life? You have to remember that there are deaf people who learnt sign language later in life and I see them...I'm not necessarily saying that coming from a deaf family means you are perfect, but is it really possible for anyone to be well? No because we were all abused by the hearing community. I mean we were and it would be wrong to say we are all well and all healthy. (Sue, professional)

However, while such extreme views were not discarded, a state of deaf wellness did exist, by which is meant a standard against which some deaf people were well and others were not. Descriptions emerged of those who were well and those who were not.

The results of focus group discussions with deaf people will be presented which explore deaf views both about deafness and about what it means to be well. Wellness was described in terms of mental well-being. While this topic appears fairly focussed, responses frequently spilled over in to cultural life experiences and anecdotes. Beliefs about wellness draw crucially upon such experiences.

As a method of collecting qualitative data, the use of focus groups were highly effective, as they allowed interpretations of wellness to emerge, in an often unexpected form, and in an indirect way. What follows is an account of wellness as members of the deaf community perceived it. Two interpretations of wellness will be presented.

The first describes those who are well and at the heart of the deaf community. Wellness is described both as a *process* and a *maintained state*. Respondents knew they were well, because they could define those who were unwell, and who were thus, also cultural outsiders.

In the second interpretation, wellness is described as being created between members of the same community. As a result, membership was less exclusive, and more widely accessible. The two examples selected to illustrate this interpretation, language/communication and identity, both served as a source of cultural celebration between members. A sense of deaf wellness, in this interpretation grew from a positive association between deaf people.

6.2 Respondents

Respondent selection procedures can be found in section 3.19.

6.2.1 Deaf professionals

The first series of focus groups constituted a group of eleven professional deaf people, working within the deaf community. All were culturally deaf sign language users. Of this group of eleven, six were born into hearing families (one man, and five women), and five were born to deaf families (four men, and one woman). All respondents were aged between 30 and 50 years.

6.2.2 Deaf young people

The second separate group of seven respondents (four men and three women) were all students and between 17 and 19 years old. All were resident at a further education college for deaf people. One person had been brought up in a deaf family and the remaining six, in hearing families. Again, all described themselves as culturally deaf, sign language users.

6.3 Procedure

6.3.1 Deaf professionals (January - March 1995)

The deaf professionals were further divided into two groups, those from deaf families and those from hearing families. Each group met twice over a period of three weeks, in a building in which the majority of respondents worked. The second discussion picked up on points raised in the first and introduced case studies as a focus for discussion. The

topic guide and case studies are included in Appendix 6 . The researcher facilitated the focus groups.

Focus groups among deaf people from hearing families took place in sign language. While the facilitator's proficiency in BSL and awareness was good, the level of discourse demanded complete access to discussion. For this reason a BSL/English interpreter was required for focus groups with deaf people from deaf families.

6.3.2 Young people (September - October 1996)

One focus group took place within the further education college. Unsuccessful efforts were made to conduct a second focus group. The focus group took place in sign and was facilitated by the researcher, assisted by a deaf co-worker. A topic guide was used and is shown in Appendix 8.

6.3.3 Analysis procedures

All the focus group discussions were recorded on video, and later transcribed into written English. In each case, the written English transcription was cross-checked by a deaf BSL user against the video recording.

The transcription text was stored in a data format and later sorted using 'Ethnograph v4.0' software package (Seidel, Kjolseth, Seymour 1988) (see section 3.25). An example of the coding categories used in the analysis of Study 3 can be found in Appendices 7 and 9. As with Study 2.2, false names have been used to protect the identity of the respondent.

6.4 Deaf and Hearing Perceptions of Deaf Health

While respondents were unfamiliar with the concept of 'deaf wellness', they were clear that their perception of what constituted well-being differed to that of hearing people. As cultural outsiders to the deaf community, hearing assessments of deaf people's health were often perceived to be wrong, and based on a misunderstanding of deaf culture. This became clear when respondents were asked how they felt about the assessment of mental health problems in deaf people:

Hearing people understand how to sign and so on but they can't really understand the needs of the individual. Many individuals do end up being given the wrong medication and so on...someone like a professional social worker who has training, just labels deaf people. They don't have an understanding of the deaf community or sign language and they don't meet a person under the same conditions that we do. We are coming from the standpoint of having been oppressed as a community so you need an understanding of what that means and how the person will react and then you can tell if it is due to oppression or to mental illness. A professional (hearing) social worker doesn't know what it is like to live and grow up as a deaf person. (Sue, professional)

> There was a deaf boy at our school. We all knew him throughout our childhood and his behaviour was really strange. We told his brother to take him to the doctor or something because we felt that his behaviour had changed and it wasn't normal. The social workers said there was nothing wrong with him and we could all see the change in him and his behaviour was wrong and yet the social worker was saying there was nothing wrong. At the same time we were saying that someone else was OK and the social workers were saying they were mentally ill, and we just felt there was a language problem. We thought the (first) person was schizophrenic, and he was eventually diagnosed as that. (Anne, professional)

Differences in perception began with the very process of observing people. In assessing health, deaf people agreed that they would examine an individual's social network as an indication of their acceptability and functioning to other deaf people. Hearing people were perceived to rely on more direct assessments of the individual:

> The important thing is that these are hearing ways of analysing deaf people. I think deaf people would probably say 'why doesn't he have a lot of friends and why don't they like him?' or whatever. *They'd rely on other people's experience of him* or classmates and whether or not he had been rejected. If people had rejected him because there was something wrong with him, then they would investigate that. (Tony, professional) [emphasis mine]

The use of case studies also demonstrated different interpretations of behaviour. For example, one case study introduced to the group involved a young man, diagnosed by hearing professionals as paranoid schizophrenic. The man, who worked as a milkman, had started to have hallucinations that Jesus Christ was following him. After a brief description of his background, both groups began to reinterpret the behaviour of this individual. They agreed that many deaf schools were traditionally affiliated with the church. It might not, therefore, have been particularly unusual for someone who had been brought up to respect religious icons and who was of low intelligence to consider Jesus Christ in quite a concrete and literal sense.

> ...he could have had a teacher who was quite religious and was influenced by that. When he left school and perhaps became more isolated, he may have wanted to see Christ. (Paul, professional)
>
> If it was someone of low intelligence you might be able to accept it, I mean if someone was always going to church, maybe they are quite religious and they really believe that, so you can't always assume it's mental illness. (Paul, professional)

Others in the group suggested that deaf people are particularly sensitive to situations in which they feel isolated:

> I'd like to go back to him delivering milk. Maybe it meant getting up really early in the morning, and he could have been worried about that. He also could have been feeling really isolated wandering around at five in the morning. He might have thought people were following him because there was hardly anyone around...because there is no communication and he's isolated and nobody understands, then he might start to suppress his feelings. (Carol, professional)

It is important to point out that the group were by no means experts in the field of mental health. Nevertheless, their interpretations of other deaf people's behaviour revealed much about dominant and in this case, hearing assumptions about normal and abnormal behaviour. There was agreement that without the experience of being deaf, cultural outsiders were not always in a position to interpret the actions of members of another culture.

The existence of differing interpretations of mental health was supported in the observation that members of the community who were thought to be well by other deaf people, were thought ill by hearing professionals. Those in the group who perceived themselves to be well, shared characteristics of those deemed mentally ill by medical professionals:

> ...again it's the same medical perspective saying that a person is mentally ill, and yet deaf people look at them and don't recognise them as being clinically mentally ill, because there are other people in the deaf community who are similar...it becomes too emotional and sensitive for us. (Sarah, professional)

This confirmed the belief that hearing judgements were often perceived to be wrong.

Having established what constitutes outsider assessments of cultural behaviour, a definition of deaf wellness began to emerge within these insider groups.

Distinctions were made between the *process* of achieving wellness, and the *maintenance* of that state. These two aspects will be examined in turn.

6.5 Wellness as a Process

Interviews with a sub-sample of the Conrad Cohort (Chapter 5) illuminated the notion of wellness in transition. Belief systems and particularly coping responses were also often rooted in earlier experiences. Within the focus groups, a similar pattern emerged. In defining the impact of earlier experiences, family background emerged as one of the most powerful determinants. More specifically, a tension was described between those from deaf families and those from hearing families. The following section examines the impact of the experience of each group and how their experience of searching out wellness differed.

Thoughts about wellness were very much tied to life experiences, for example, to family upbringing, school, and attitudes towards hearing people, and were all pertinent to a consideration of wellness.

6.5.1 Deaf respondents of deaf families

Deaf people from deaf families were perceived by those deaf people who were not, to be the core of the community.

> I think before there was a strong core of those from deaf families with deaf parents. I mean I arrived in X school and saw all the ones from deaf families and I was the outsider struggling to get in, but I kept on trying and eventually they got used to me. (Clare, professional)

Their insider status within the deaf community meant they often had access to what was described as privileged information about the world:

> I mean, I grew up in a deaf family and I saw my parents coming home, walking around and talking about work and everything, and they worked in the hearing world so I knew. I was prepared to go to work, I had learnt from their experience, so working life was not a shock. (Paul, professional)

Those from deaf families, while holding privileged positions as core members of the deaf community, were in a position to isolate aspects of this experience that had a negative effect on a developing experience of well-being. For example, there was agreement that as children, those from deaf families were more exposed. One respondent of deaf parents claimed membership of a relatively small community meant his behaviour was monitored and behaviour which violated cultural acceptability, always reported back to their parents.

Another view which generated a mixed reaction, was that those from deaf families, unlike deaf people from hearing families, had not had the benefit of being able to grow through the experience of suffering. As a consequence of being brought up in a very protected environment, they chose easy options, rather than challenging ones:

> Some people who have been raped or who have had other bad experiences can become stronger people, and maybe we haven't had enough suffering, that could be one reason why we head for safe jobs. (Anne, professional)

As will become clear, those from deaf families nevertheless acknowledged their powerful status. Unlike those from hearing families, they were born into the deaf community and therefore had first hand knowledge of cultural beliefs and behaviour.

6.5.2 Deaf respondents of hearing families

All those who participated in the focus groups described themselves as culturally deaf. For those who had been brought up in hearing families, a transition had occurred between their family and an adult deaf community.

The concept of such a transition was introduced in Chapter 5. Within the context of a focus group, migration among deaf people from hearing families to the deaf community is presented as a key aspect of deaf experience.

There was wide agreement that many deaf people suffered as children, and that in reaction, they identified a need to reject situations of suffering, experienced earlier in their lives:

> I left school and I knew nothing. I didn't know who I was, I knew nothing and was very withdrawn. I stayed inside the house a lot walking round, watching TV all the time. Other hearing people were around and I would ask what was being said but I was given no information...in a way before my home was my jail... (and now) maybe there's some link there but no, I've forgotten my parents, flushed them out of my mind. The link with them has completely gone. (Bill, professional)

In confirmation of this experience, many deaf professionals from hearing backgrounds were extremely hesitant about working, for example, in the field of deaf education, a place they associated with their own and other's suffering. There was a reluctance to associate themselves with the memories of such experiences:

> X school wanted deaf people to get involved with the teaching and I went once and felt that I couldn't do that, I felt that I was going back in time. There was a lot of suffering because I was looking at children experiencing what I had experienced and it brought back a lot of bad memories. That's a sensitive thing for us to cope with. People don't want to go through those experiences again, and I think that is why it's a problem area. We don't want to associate ourselves with the painful experiences that other deaf people are experiencing, or other deaf children. (Anne, professional)

> ...I think education is one of the worst areas for biased opinions, it makes you cringe, your hair stand on end, because the education establishments are the most oppressive places for any deaf person. People just don't want to work in them because there are such painful memories of their own education. (Sue, professional)

All those in the deaf student group had left full time education one or two years prior to the focus group meeting. Their experience of types of schooling was diverse, respondents having attended hearing schools, integrated units, and both residential and day schools for the deaf. As with the group of professional deaf people, there was wide agreement that school had been a bad experience. Again, many felt they had suffered as a result of oralism, and more specifically, at the hands of hearing teachers, thought to be "obsessed with hearing":

> They (the teachers) expect you to use residual hearing but my hearing is just not good enough, it was a waste of time. They are obsessed with hearing, really! I told them that I could hear absolutely nothing. I threw away my hearing aids when I was 13. That time I was at a PHU for about 4 years. I really suffered, and felt oppressed, I was also frightened. I had a huge hearing aid around my chest and I used to get so angry. (Sam, student)

As a consequence of this experience, they described feeling drawn to situations which promoted a feeling of wellness.

For the most part, the most significant encounters with hearing people had been with hearing professionals. The deaf professional group, particularly, was disparaging of the power that hearing professionals had to make decisions affecting deaf people's health. The younger group was in agreement that hearing professionals could be blamed for their role as agents of oralism:

> I agree with what was said before, if hearing people want to be involved in our community, then they have to accept our way of doing things, our theories or whatever, just as we had to accept oralism. If we don't accept oralism then how can we be part of their community? If they also reject things then it's impossible for a link to be there. If they accept sign language, and have a good attitude and so on then we will accept them. If they criticise things then there's no way they can be accepted, sorry, but it's not good enough. (Lee, student)
>
> If they have a really amazing attitude then OK, but if they have a bad attitude, maybe they try and put deaf people down, then they can stuff it. If hearing people want to join the deaf community to see what it's like then I don't mind, it's their choice, but we should be free to make them suffer as they have made us suffer in their community...I feel that in the future things will improve. In the past people suffered through oralism, through discrimination and being labelled mental or something. (Sam, student)

Younger and older deaf professionals recognised that they were more likely to feel happier around other deaf people and so chose to associate with other deaf people:

> But you don't have to talk to the hearing in school, I mean fuck the hearing, if there are deaf people, then get on with meeting more deaf people. (Sam, student)
>
> I was quite surprised I mean it's quite depressing in a way, that you spend 6 years being really confident around hearing people and then realise that it's nothing compared to how you feel around deaf people. That was only after three or four months! (Lee, student)

In some respects, young people believed that their generation was different, and had a more positive attitude to hearing people:

> Before, it was a very closed community, and there was an awful amount of hostility towards hearing people. Our generation is changing; now we accept hearing people more, the balance is changing. That's quite a big change. Certain things will never change, like the strong deaf culture, but how we then go on and relate to other people is changing. We are more involved with hearing people, but our culture won't change. (Lee, student)
>
> I don't mind if hearing people get involved. A few hearing people have told me that they go to the deaf club or whatever and sign and deaf people come up to them and ask if they

> are deaf or hearing. When they say they are hearing they just ignore them. I know it happened before but I think that's a bit strange but I don't mind myself. (John, student)

There was "more of a relationship with hearing people" (Sam, student). Where before almost all contact was perceived as being related to an ongoing process of oppression, things were now more equal; the situation had improved, to the point that hearing people with the right attitude could:

> ...act deaf because they have deaf culture inside them. They understand our way of thinking - the deaf way. It comes as a surprise to find out that they are hearing and not deaf. If you follow the deaf way you can think like deaf people. (Lee, student)

When asked if they would rather work with deaf or hearing people, most replied that they would still rather work in the deaf world. When this response was investigated, certain conditions emerged. For example, the first priority was finding an appropriate job, and only after that would a choice be made to work with deaf, with whom communication would be easier.

The groups of older deaf professionals were either single or with deaf partners, and considered this to be a condition of wellness. Those in the student group envisaged having a deaf partner in the future, however hearing partners were not ruled out, but were subject, again, to certain conditions:

> Most of me hopes she is deaf but if the person is hearing then that's fine as long as she can sign. If she starts speaking to me then she can fuck off. Deaf is fine. A hearing person with deaf inside them - why not? (Lee, student)

Experiences within the family were more diverse and anecdotal. Older deaf people from hearing families confirmed common experiences of incompatibility in their lives as children and as adults.

The group of younger deaf people also shared strong beliefs as to the acceptable and unacceptable within the home. Many were familiar with experiences of isolation within the family, and were unequivocal about both the unacceptability of the situation, and of the damage caused:

> I argue with my father all the time, there is a real communication breakdown. With him it's a waste of time. With my mother I can sort things out, but with him, no. My father never learnt to sign, he's really lazy. (Jamie, student)

The style and content of discussion between younger and older groups often echoed one another. For example, several members of each group, described how their mother often represented sole access to the family:

> I think there were some stressful situations. I mean, my mother signed and used to interpret for me, but my father never signed, and neither did my brother. I would sit there watching them talking and I wouldn't have a clue what was going on. I'd keep nagging my mother to tell me what they were saying and I'd get so stressed out. I really wish they'd learnt to sign. (Jamie, student)

For both groups, descriptions of childhood were characterised by difficulties in communication, feelings of being overprotected, or isolation.

Some differences emerged between the student and professional groups, influenced, in part, by generational factors. Younger respondents were not only of approximately the same age but had all recently left home. The professional group was more disparate, and while sharing much in common, had slightly more diverse backgrounds. Differences were also, in part, a result of social change. Relative to the older group, students had discovered their deaf identity much earlier in life. This had been facilitated by their entry into a college exclusively for deaf people which openly attempted to cultivate a sense of deaf community.

6.5.3 Movement from family to the deaf community

The process of wellness, particularly for those from hearing families emerged during childhood. There was clear recognition that at the very least, the basic need for communication had to be fulfilled outside the family, and an agreement emerged that in order to be well, it was necessary to mix with other culturally deaf people. Consequently, both older and younger groups agreed that adverse experiences in childhood and mixed relationships with their families, had led them to recognise primary allegiance with other deaf people:

> My parents are always nagging me to spend more time with them but I put deaf people first. I tell them to hang on while I go out and have a good time with deaf people! (Clare, student)
>
> I find that my first priority is with the deaf world, because I am deaf myself. before I think it was different and I used to think that the hearing world was the bees knees, but that's changed now. (Sam, student)

Between older and younger deaf people, the subsequent transition typically took different forms. Professional deaf people reported an uprooting from the family, and to the deaf community, describing often functional advantages in transferring allegiance to the deaf community. For example, other deaf people were able to fill in gaps in information:

> I tried to ask my parents things but they couldn't give me the right information so I would go to the deaf club and ask around and they gave me all the information I needed, so I gave up on my family. (Bill, professional)

In these circumstances, the transition was total, with both emotional and practical aspects. For one or two respondents this process actually involved severing all ties with the family:

> I just didn't feel that they accepted me. Communication was always oral. Because I became deaf later, I can speak OK, but I really begged them to learn to sign and they totally ignored that, so, you know, the link has gone; they never understood me, or accepted me. Really, they treated me like shit, they can forget it...confidence or encouragement from them was non existent. I just couldn't cope, there was no real contact there. With the deaf I feel more comfortable, more relaxed, I can do what I want. With the hearing I sometimes feel unsure. I try but I just don't feel that confidence. (Steve, professional)

Unlike the groups of deaf professionals, many of the younger students were more open to the possibility of change. While they recognised that a transition had occurred, it was rarely complete. In their relationship with parents, there was optimism that while they continued identifying primarily with the deaf community, their parents could "catch up".

In some cases, it appeared that the family actually moved with the child some way towards the deaf community. The situation presented by younger deaf people differed significantly from that of the relatively older groups; the latter's view being that the individual alone moved between the family and the deaf community. To an extent, this pattern reflected the age of respondents. Those in the younger group had all recently left

home, and clearly the social and political climate in which their parents discovered deafness differed from that of the older respondent group. Particularly within the student group, many were sympathetic to the situation their parents were faced with. For example, Lucy reported her parent's initial refusal to sign as a result of their fear of being cut off from her:

> I was born deaf, problem was talking, I didn't talk until I was about six. My parents were worried and took me to a speech therapist who tried to help. They didn't know what was wrong. They eventually found someone who could help. They came and asked my parents if they wanted me to lean to sign. My parents refused, and just said that they just wanted me to learn to speak. They said they didn't know how they would communicate with me if I was taught sign language...now my mother wants to learn sign language because she's come to love deaf people. She worked at my old school so I saw her at lunch times and break times and so on. She really wanted to learn from the deaf children there. (Lucy, student)

Between the professional and student groups, differences emerged as to the factors that instigated their movement towards the deaf community. While older respondents prioritised factors linked to their emotional needs, for example, to be accepted and to experience belonging, for the younger group, language was the key. Consequently they actively sought out situations where the use of sign language was dominant, and were scathing in their references to their predominantly oral education.

While not all members of the group of young people claimed to have experienced suffering themselves, there was agreement that experiences in childhood, particularly those of deprived access to language, had a strong relationship to experiences of illness in later life. For example, the following comment was made with reference to parents who deny their child sign language:

> If parents treat their deaf child like shit and don't communicate with them, then when they grow up, they'll have mental health problems - they may end up in a mental hospital - it's a simple as that. (Clare, student)

In celebration of this new found identity with other deaf people, oral skills are dismissed as reminders of former times:

> I remember the teacher came round to the school again and we were all being taught orally. She hit the roof and told us again that sign language was an important part of our

> deaf identity and personality. For the year after that I learnt sign language and spent time at the deaf club picking up more signs and mixing with other deaf people. I really felt that I had found my deaf personality. I didn't have to follow hearing people anymore; I could be involved in the deaf world and be really confident. I never thought it would happen but I'd never go back now! My life is with deaf people and sign language. I can express myself so much better - the first time I had been in a situation where everyone was deaf and I felt really comfortable. (Clare, student)

6.5.4 Point of transition

Of those who described transferring allegiance to the deaf community, most could identify a specific moment of change, or a point in time, when things changed. Whether or not the change occurred at one specific time or not, descriptions of life developed 'before' and 'after' labels. The transition was understood to symbolise before and after achieving membership of the deaf community, which may be equated to before and after experiencing wellness.

For many of the older deaf people interviewed, this time of change occurred when they started going to the deaf club. For the younger students, such a change was defined by entry into the college:

> At school I felt exactly the same way all through, but then when I moved schools everything changed. I suddenly felt very much as if I belonged to a big family. (John, student)

The experience of entering the college and being immersed in a deaf community was clearly heightened by coinciding with the first period of independence:

> It depends on their background, I think deaf culture is something that happens to people when they go to college and are more able to decide for themselves and make choices about certain things. At school, teachers tell children what to do and what to think. At college you are more independent and you can make decisions about what you want to do and think. (Lee, student)

Descriptions of the transition, or self-discovery, from traditionally hearing family culture to the deaf community, confirmed that entry into the deaf community was not automatic but rather they had to work to achieve membership. This was particularly evident among the professional group:

> I went off to X oral school and so I was a late entry into the deaf community. I struggled like hell until eventually they accepted me. (Steve, professional)
>
> I am from a hearing family and went to an oral school. I went to the deaf club the first time and they accused me of being hearing, and I lost all my confidence. I wanted to be accepted as a deaf person. I had to struggle to get included. Today I feel better than before. (Tim, professional)

For those who joined the community later in life, the process of achieving membership had often been traumatic. As the comment below illustrates, many deaf people from hearing families initially experienced feeling homeless, stuck in the middle of the two worlds, not understood by hearing society, misguided by an educational system which claimed to equip them for the hearing world, and then rejected by the deaf community:

> Imagine, you go to an oral school and they teach you how to speak, they send you out into the hearing world and people don't understand you, and so they say you should go to the deaf club, and people there just don't accept you. (Steve, professional)
>
> Those who have a mixed identity have the most severe problems. They don't know where they belong and really they are the worst kind of people...those deaf people who have a mixed up or confused identity are the ones who have problems. Really we have to stop and ask what their expectations are and where do they belong? (Anne, professional)

Despite reporting difficult journeys towards the deaf community, all those in the focus groups considered they had "made it", and achieved membership.

To recap, the transition, while often coinciding with growing up and leaving home, was loaded with much more significance. That is, the significance with which each individual awarded the transition was enormous. The transition may be seen to represent movement from the hearing world, incapable of satisfying basic needs associated with wellness, to an environment that was optimal for wellness.

For most, the journey towards a state of wellness did not stop once they had joined the deaf community. They acknowledged a hierarchy within the community, in which individual deaf people occupied various positions in relation to one another. The experience of wellness was described as being dependent on an individual's location within the community. The following section will explore this in more detail.

6.6 The Maintenance of Wellness

Discussing the existence of wellness illuminated the intricate relationship between the maintenance of wellness and the structure of the deaf community. Two interpretations of the maintenance of wellness emerged, which will be considered in turn. The first interpretation defined wellness against that which it is known *not* to be; consequently, those described as well could be separated from those considered unwell.

The second interpretation is based on reports of positive features of deaf culture, or components of the cultural experience of deafness, which merge to create a state of wellness. The second interpretation allows deaf wellness to be experienced more widely within the deaf community, as it was not bound as closely to location within the community.

The following section explores the first interpretation, focusing on three areas: coping, the insider/outsider distinction and the existence of actual and conceptual territories.

6.6.1 Coping

There was an agreement, across the groups, that rather than being described as well, if a deaf person could *cope*, then they were actually well. Deafness in a hearing world was recognised as creating stress, which affected all deaf people. How this was consequently negotiated, reflected the individual's degree of wellness:

> I don't think that deaf people in a hearing world can be completely well; if people can cope then that's what we mean by wellness. (Sue, professional)

An inability to cope, therefore suggested illness:

> If a person cannot cope, then their minds go wrong. They need support to control their life again. (Sam, student)

In the most extreme form, those with a mental health problem were considered to be fundamentally unable to cope (unable to achieve wellness).

6.6.2 Insiders and outsiders

Recognition of coping, and therefore of wellness, suggested insider status within the deaf community. In turn, as we have seen, membership was not automatic but defined and decided by members of the community.

Those who were insiders to the deaf community defined their membership in contrast to those considered to be outsiders. The process of maintaining insider status was characterised by the exclusion of certain deaf people. One way in which this was done was through systematically labelling those thought to be unwell. Indirectly, this appeared to confirm insider well-being.

Across all the groups, respondents traced the roots of labelling processes to school, where certain people with particular traits were labelled and excluded:

> At school there were some people who could never get into groups...why?, maybe because we didn't like them or they were different, I don't know, but they were pushed away...like those with good hearing who we called the 'hearies' and we told them to get lost, or those who were clever or cocky...we didn't really want to know them, but we didn't really give them a chance...thinking about it we definitely excluded certain people. (Clare, professional)

Both those from deaf and hearing families recognised that they were in a position to label those perceived to be more peripheral within the community. For example, those from mainstream school backgrounds (with a weaker deaf identity) were typically peripheral:

> The deaf who were mainstreamed, when they came, to be honest, we labelled them. We used the sign for audiologically deaf rather than culturally deaf. (Paul)

The following section examines two groups within the deaf community: deaf people from hearing families, and deaf people with additional needs. Evidently, the location of each group, often on the periphery of the community, served to confirm the location of those at the heart of the community.

6.6.2.1 Deaf people from hearing families

Those people from hearing families described those from deaf families, as being core members of the community. Those from deaf families were clear that being raised in a hearing family affected an individual's ability to cope, in this example, with the day to day realities of work:

> Everyone had the same experiences so you'd just get on with it. Deaf children with hearing parents, they try and cope in a different way, maybe an 'oral' way, but they don't necessarily have a strong identity or language, so when they get home they don't get any support. Their parents will just say 'Never mind' or will patronise them about problems at work and so they will really get frustrated and let off steam and then in the end you think 'Gosh, what was all that about?'. When deaf children go home to deaf parents, they can talk and share experiences and begin to understand about going out to work and what it actually entails, so I guess they don't encounter as many problems in the work environment. (Sue, professional)

Many examples were cited in which those from hearing backgrounds had alluded to aspects of an outsider identity. As wellness was associated with insider status, these reports served to confirm that those from hearing families were perceived to be less well than the deaf insiders. The following example illustrates this reasoning. Deaf people from hearing families, in describing their education as oral, were perceived to imply reticent pride in oral skills, which contradicted the beliefs of the deaf community:

> What I've noticed is that a lot of them from hearing families are very bitter, very bitter and have a chip on their shoulder, because of their past experiences and the way they have been treated...but we aren't, and they say things like 'I went to an oral school' and I say 'I went to a deaf school' you know and I'm proud of that and I never really considered PHUs...I'd say a deaf school... (Carol, professional)

As a result, deaf people from hearing families, unlike core members, were perceived to be less confident and unsure who to trust:

> ...deaf people from hearing families ask everyone their opinion because they aren't sure, but a deaf person from a deaf family will ask just one person. (Carol, professional)

Other core members considered those from hearing families, to be over reliant on their parent's advice, above the advice of other deaf people:

> I've noticed that deaf people from hearing families always say "My mum and dad said..." which makes me angry, I mean you can't help someone who wants to just listen to their mum and dad all the time. Deaf people from deaf families, we would never use that term, and that's one difference in emotional problems. (Sarah, professional)

Again, allegiance to hearing culture was thought to imply weakness.

Despite an often difficult start in life, those from hearing families could, however, *learn* to cope. While they were perceived by core members to be peripheral, they were not totally excluded from the community. Often their source of information was actually core members. From childhood, there was recognition that those from deaf familes were 'gatekeepers' to the community, maintaining and imparting knowledge and beliefs:

> I think I got my support from children from deaf families. I used to ask them things, or ask someone to ask them things, I didn't know anything at all. I would stick by them in admiration, and if one didn't know then I would ask another. When I think back, it was the people from deaf families I would follow around. I would try and get information from them. I would go to their homes and would be looking around, I loved it! (Clare, professional)

As detailed in section 6.5.4, searching out wellness was rarely straightforward for those who found themselves on the outside trying to get in. Just as anger and frustration accompanied the experience of initially gaining admittance to the deaf community, so too, those from hearing backgrounds suffered in their experience of negotiating their location within the community:

> I was talking to a deaf person recently who was saying 'you should sign with your family/children' and I thought 'no that's not right, my children are hearing and I have to respect them for that'. That person felt really torn. I told her, she was from a deaf family with a tradition of deafness, but not everybody's background is the same. It's very easy to say but I think there is a real problem...a sensitivity there, I mean everyone is different. (Clare, professional)

6.6.2.2 Those with additional needs

Those with additional needs were also often located at the periphery of the deaf community, however, the nature of their exclusion provides another example of the dynamic process through which wellness is defined. In labelling peripheral or outsider groups, core members of the deaf community confirmed their insider status, and therefore their health. The following examples report the treatment of those with additional needs:

> I went to the BDA conference and they were talking about the deaf coming out of their shells, but what about those left inside, the deaf in wheelchairs, and the deaf-blind, they have just been abandoned. We think we've done OK but what about those groups, we have rejected them. (Steve, professional)

Similarly, the presence of an individual with mental health problems at the deaf club on the social night was thought to be wrong, and respondents felt unable to include her:

> Deaf people who have been labelled as mentally ill, like the person I was referring to before, still go to the deaf club, but deaf people don't talk to her. They are fed up of her constant demands for attention, and always wanting to talk...the other deaf say to each other 'Oh crikey...' We need the time without her. I mean, it's good to see that person so happy but at the same time we do get fed up with always being interrupted. She is always demanding things. It's maybe because we want to relax and we don't want to be bothered. It means more than that - it's the wrong place or the wrong night. (Sarah, professional)
>
> There are a lot of deaf children who don't want to be associated with children with other disabilities and it's like that in the deaf club. We aren't interested, we don't want to know. I go to X to visit a member of my family because I know that when I go to see her I am giving her time, and I enjoy seeing her and other residents. When I go to the deaf club, I think "what are they doing here, it's not the right time or the right place". (Sue, professional)

Particularly for those with additional problems, two factors appeared to affect their acceptance. The first was whether the additional problem, such as mental illness was *permanent*. The second factor, which affected acceptance, was whether the individual had been an insider; that is, had been accepted *prior* to their illness.

Those whose difference or disability appeared to be irreversible appeared to be more often excluded. There was an implicit suggestion that their ability to cope had been damaged and this had implications for the amount of support they might need, beyond that which the community could provide:

> I remember a friend of mine at the deaf club who suddenly became blind. You know, before that he used to work in the bar, and he was quite active in the deaf club. When he became blind, I mean what happened was that he just ended up being alone in a corner, and nobody would talk to him. Sometimes people can't cope with other people who have changed. It's hard for individuals to accept change in people. (Steve, professional)

Contact with the community prior to their illness also affected the deaf community's perceived responsibility for the individual :

> ...if they were going to the deaf club and then were mentally ill, and were coming back into the deaf club, then the deaf community would be able to help them bring their strength up again, bring their wellness back. (Anne, professional)
>
> I feel that if you had actually known someone then you feel that you can actually communicate with them and associate with what they are going through. They might have had a problem before or whatever, and that's important but if you have never met someone before, you might find them unapproachable and they might get quite annoyed at the fact that you have approached them? (Sarah, professional)

This conditional acceptance is clearly illustrated in the quotation below, which reports a deaf person, active in the community, suffering from a nervous breakdown. While there was an agreement to 'hush up' the fact that an individual had *become* unable to cope, there was an understanding that the deaf community would continue to support that person whose acceptance had already been established:

> My husbands' mother, who is deaf, had a nervous breakdown and just couldn't cope. She went to the hospital and we all kept quiet. When that happened, we really couldn't tell anyone. She was involved in a strong deaf community and there was an agreement to keep quiet. We would tell people she had been in hospital but that she was taking tablets and would be all right now...we had to protect her. (Anne, professional)

In summary, it would appear that the position of core members of the deaf community is confirmed by the recognition that certain groups occupy a peripheral, if not at times, outsider location within the community. Wellness is associated with insider status and may be seen to be contingent upon the ability to cope.

Having considered those in a position to experience deaf wellness, the following section will examine the location of wellness, and the existence of actual and conceptual boundaries to it.

6.6.3 The location of the deaf community - actual and conceptual space

In all the groups of younger and older deaf people, respondents located the deaf community in one particular place. While constituting a congregational area, a deeper relationship developed between this space and being well. This place had the properties of an actual building, and also of a conceptual area. However, for the younger and older groups, the locations, while sharing many of the same properties, were not the same. For

the younger respondent group, this place was the college, and for the older, professional group, the deaf club. The deaf community held certain resources which were intrinsically linked to these locations.

The following section will examine the location of the deaf community from two perspectives; as an actual building and as a conceptual space.

6.6.3.1 Actual space

As the place where traditionally deaf people have met, for the deaf professional group, the focus of the deaf community was the deaf club. For those from hearing families, the deaf club had typically gained significance later in life. For those from deaf families, the deaf club had always been the central focus of social activity.

> I sometimes wonder why I say to myself 'I must go to the deaf club' and I think it's because it was the only place my parents ever took me from childhood, just to the deaf club, not to the pictures or anywhere else... (Sarah, professional)

The deaf club was described as being both a home and a safe place to be among other deaf people. As such, the relationship between the sensation of wellness and the actual building was fairly explicit. Within the building, sign language was the only language used, and all respondents reported the ease associated with being around other culturally deaf people:

> ...the only time I can relax is at the deaf club, I want to be me and relax and have fun and do whatever I want, in my own language. When someone approaches who doesn't share my language, I'm not interested, you know, it's not my problem...it's their problem. (Carol, professional)

> I tried to ask my parents things but they couldn't give me the right information so I would go to the deaf club and ask around and they gave me all the information I needed. I still go to the deaf club, it's my first home, if not for that I'd be out in the hearing world with a job faking it. (Bill, professional)

The deaf club possessed an almost magical ability to restore strength. Deaf people arrived feeling under stress, and left feeling relaxed and rid of their frustrations.

> I think, well, if something goes wrong I'll be OK, I can write it down, but when you walk into the deaf club that feeling disappears, that feeling that something might go wrong. If

you ask why I go to the deaf club, I can tell you it's because it's my second home. (Anne. professional)

...if we got frustrated with the car not working or getting petrol or whatever then we would arrive at the deaf club and all our frustrations would go. It's like a form of treatment really...although they weren't always interested, we have very close tight-knit community, and people do support each other. (Sarah, professional)

...when they [deaf people at the club] go home, they have got rid of all their frustrations - all their problems are resolved at the deaf club. If there was no deaf club then that would be a great problem. Maybe you think that that is a problem but they actually feel better afterwards. At least they can off-load at the deaf club, and that's wellness surely? (Paul, professional)

Younger deaf people displayed the same need for this space, defined by boundaries of admittance and sustained by the use of sign language and by common cultural beliefs. The younger group had created their own space, which in its emotional support and sense of belonging, very much resembled the deaf club. While this place was primarily the college, they also reported congregating in pubs. Within this space, they "talked about all kinds of things" and felt "like a family" (Sam, student).

We're always together. When young people get together they talk about all kinds of things, whereas the old people in the deaf club just talk about their wives or husbands or whatever, or the old days or the war and it's boring. (Lee, student)

Before I came to X, when I imagined going to the pub, I imagined getting pissed, getting into trouble and so on; that was my view of pubs. When I came to X, that all changed. Now I know that being in the pub means meeting deaf people, socialising and not necessarily drinking and getting pissed. The atmosphere in the pub with other deaf people is so different from the deaf club! It's a young people's atmosphere, and we feel happy. On a Wednesday evening we really do take over the pub, honestly! It's virtually all deaf people. (Jamie, student)

Younger deaf people recognised that their own cultural needs as young people were different from those of older deaf people. For younger deaf people, the location of their community was more transient, and actual space was not prioritised. While describing the same need for conceptual space, that is, an area in which association is based on identity and a common need, generational differences kept the two groups apart on other levels. Experiences at the deaf club, for younger people, were consequently often unhappy:

I remember the first time we went to the deaf club, it was the first and the last time...we went in quite a large group, but they just weren't interested; they acted like we just weren't there, just ignored us. They never included us in conversation, like saying welcome to X deaf club, this is what we have to offer etc. We didn't know what was going on. (Lee, student)

I once went to the deaf club here but I felt that I was really not welcome; we weren't part of the club so I guess I felt that it wasn't our place. They weren't nice people. That's why I don't get involved. That's why no young people go there. I understand why. (John, student)

Young people perceived not only the predominance of older deaf culture, but a disparaging attitude towards their behaviour:

> Yes, it's mainly old people now and they really leave young people out. They have set ways of doing things and there's no compromise, no change. They say 'that's the way you have to do something and if you don't like it then tough!' Well I feel like telling them to stuff it! It's the same, no it's worse here. Although they (deaf club) have a bar, I prefer to go to the pub. It's a better atmosphere, I mean in my home area it feels like an old people's atmosphere and it doesn't suit young people, it's a barrier. (Lee, student)

Young deaf culture was contrasted with that of the older deaf community in different ways. One person explained that if they met another deaf person for the first time, they would find out where they were from and work out who they both knew and so on. The next time these two people met they would hug and "chat for hours". Many perceived older deaf people as displaying no physical affection "they sign and chat to each other, but that's it" (John). The students perceived that older deaf people considered hugging, something that was wrong, "like a sexual thing"; that it was alright in the family between parents and children for example, but not between friends.

Despite tension between the generations' perceptions of each other, the need for this space by both younger and older deaf people was evident, therefore both groups awarded great significance to places which allowed the experience of wellness to emerge.

In contrast, deaf people who remained isolated from other deaf people, and especially the deaf community, were somewhat of an enigma. Even when this was known to be a conscious decision, doubt was raised about their ability to ever relax and switch off:

> ...some people say that they don't want to mix with the deaf community, they only want to be with other people who are on the same wavelength, but that's not a healthy thing. You know, they're always talking about politics and stuff and it's not always good to be under that kind of pressure and stress all the time. (Sue, professional)

Similarly, there was intolerance for those who violated the rules of the actual space. For example, oral deaf people were rarely accepted by signing deaf people. Their presence alone verged on being threatening to deaf people, clearly protective of their space:

> If there is an oral deaf person at the deaf club, I would just ignore them, I don't bother chatting to them. I go to the deaf club to chat to people who share the same language as me- to be honest I try and ignore them. (Carol, professional)

The following section will explore the notion of conceptual space, and its bearing to the perception of wellness.

6.6.3.2 Conceptual space

Descriptions of the deaf club and the college suggested that beyond constituting a meeting place for deaf people, each had a deeper symbolic value, constituting territory on a conceptual level, to respondents. This conceptual space operated both on an individual and a community level.

On an individual level, attitudes towards hypothetical case studies were revealing. A case study was presented to the professional group in which a man displayed traits of psychotic illness. The account included reference to the fact that the individual was physically isolated from other deaf people:

> There is no mention of him going to the deaf club or meeting deaf friends, so you assume he didn't and that could have created mental illness. If he had gone to the deaf club or he had good deaf friends and so had communication he wouldn't have become depressed. (Clare, professional)

Clearly, the absence of community with other deaf people was thought to be a potential cause of his illness.

As the two quotations below illustrate, the knowledge that the club was a constant resource, sustained deaf people, even in their absence. The deaf club took on the properties both of a resource and as a panacea:

> If I hadn't have had the deaf community when I was away then that would have had a greater effect. If they hadn't have been there then I don't know what might have happened to me; the possibilities are that I would have had a breakdown or given up the job and gone back to an ordinary sort of job and given up a professional career. (Anne, professional)

> ...it's important to be able to relate to people in the deaf community, and I feel that that is part of wellness. The deaf community is needed for people 24 hours a day, seven days a week and without it you can't really survive. (Paul, professional)

The boundaries of conceptual space, on a community level were most apparent when under threat. The presence of hearing professionals represented one such threat. As cultural outsiders, they were often an imposition, unwelcome because they brought the hearing world into the deaf club:

> There's a group that come every Wednesday to the deaf club and the (hearing) staff come and sit them down and ask them what they want to drink and then they just leave them. I get quite upset because if I was a deaf person leading this group I would ask them if they wanted a drink and then say 'Come on then, come up', and I would introduce them to people and get them to get their own drinks. I'd try and have some sort of relationship with them, I'd talk to them about deaf people and the deaf community, but the hearing person comes along and sits there and thinks, 'Well, it was my job to bring them here, that's it'. Then they get upset when the group just sits there and don't mix with the deaf community. (Carol, professional)

Hearing people were seen to attempt to control interaction, and therefore the structural dynamics of the deaf club. Although not stated explicitly, the implication is that the presence of, particularly hearing professional outsiders, disturbed the expression of wellness:

> I just wonder how that situation has arisen. I mean who is deciding when those deaf people can go to the deaf club - is it hearing people? Have they asked deaf people and the committee if they agree or not? I kind of wonder who has set this situation up? Who is controlling us like puppets, pulling our strings? We just have to cut those strings right off, and mix however we want to mix. (Tony, professional)

Disturbance was perceived both in the treatment of subgroups within the community (section 6.6.2), and in how wellness was expressed within the actual space of the deaf club (section 6.6.3.1).

By contrast, a deaf professional in a similar situation, aware both of the boundaries in existence, and of his role in mediating between groups, behaved in a manner as to sustain the structure of interaction, and therefore respect this space:

> ...when the deaf person brings them along there is such a difference in how the groups relates to the deaf community and how they relate to the group....there are one or two that are a little bit aggressive and there is a deaf-blind person, but the deaf person explained all about them...it's really important to have a deaf person mixing with a group of unwell people. (Sarah, professional)

In summary, while the deaf club or college represented a very real location for deaf people to associate with one another and celebrate wellness, this space also sustained conceptual significance. As a conceptual space, it was a resource base, incorporating a sometimes-exclusionary system of boundaries. The conceptual value of such space was most clearly exhibited when such boundaries were threatened.

6.7 Positive Views of Wellness

A second interpretation of wellness emerged, less well developed in the text, in which wellness was perceived to evolve as a result of *positive* affiliation between deaf people. That is, wellness was an energy created between members of the community. The following section explores this interpretation of wellness using two examples, firstly, references to language or communication and secondly, through references to identity.

In each example, two aspects emerged. The first presents both language/communication, and identity as tools acquired in order to cross the boundaries into the deaf community; the second, presents each as a source of strength, and as part of a celebration of deaf culture.

6.7.1 Language and communication

6.7.1.1 Language and communication as a tool

The importance of communication as a vehicle for growth was discussed from different angles. There was agreement among the professional group that without language and communication, an individual would be incapable of making the transition from the family to the deaf community (referred to in section 6.8).

Communication was vital both to achieving a state of coping, and to the maintenance of that state, as the following example illustrates:

> What I've learnt is that I'm happy with this situation and I know it's stressful and research is a lot of hard work but my heart is here because I have communication and without communication I don't think I could cope now, because with communication you also have knowledge. I look back on the days when I worked in a factory; I left school at sixteen, and I only really knew about family issues. I don't want to go back to that, I would rather be on the dole than take a step back. (Sarah, professional)

Situations in which communication was blocked, inevitably provoked anger. This response was understood both from respondents own experiences, and recognised in other deaf people. Deprived access to communication therefore provoked strong sympathy. In one case study presented to the older groups, a young man becomes violent towards his father, with whom he cannot communicate.

> ...the point is that most of his aggressive behaviour is towards people who can't communicate. His father, for example, and his work mate. That brings on frustration and the aggressive behaviour. (Steve, professional)

To one man, this story provoked experiences reminiscent of his every working life:

> Where I work I get frustrated and angry and start banging on the table because of the lack of communication. If my behaviour was the same with the deaf then yes I'd have a problem and would be unable to cope. But I am two different people. I have to cope with that and with situations where communication is blocked, when there are communication barriers to good communication in every direction. I become aggressive in those situations. (Steve, professional)

Communication, namely sign language, was considered a means with which to access the practical and emotional resources of the deaf community. Without this tool, insider status is denied and the individual's response is typical of 'illness behaviour'.

6.7.1.2 Communication as an aspect of culture

Beyond providing access to the deaf community, the use of sign language reinforced the exclusive properties of membership of the deaf community, and in this sense could be described as a positive requisite:

> If you have got communication then you are obviously going to be well, if you haven't got communication you become frustrated, isolated and depressed but it's to do with that shared understanding - it's more than language, so having no one to talk to would be 'not well'. (Paul, professional)

Sign language, as a positive aspect of culture was shared between people, and was associated, not only with functional communication between deaf people, but with relaxing and with bonding:

> If it had continued another year, working abroad then I think people would have been visiting me in a psychiatric unit because I would have been mentally ill! I mean, yes I had a social life...but we didn't share the same language or culture and so couldn't relax - that magic was gone. (Sarah, professional)

In this sense, communication created and sustained wellness.

6.7.2 Identity

As with language and communication, references to identity suggested two interpretations. The first considered identity as a means of accumulating resilience or strength, perceived to be necessary in order to cope with living in a predominantly hearing society. The second perspective, as with language and communication, describes a deaf identity as a positive aspect of deaf culture.

6.7.2.1 Identity and resilience

Discussion dwelt upon those whose identity, and consequently resilience, was perceived to be weak. The concern was that without the strength associated with resilience, individuals ability to cope was considerably reduced:

> Maybe people will reach the age of forty and still have identity problems. For me, you know, I had to run all my life in order to keep up with hearing people and now, you know my life has run on without me, not being able to control it, and I keep messing up all the time. (Tony, professional)

For the younger deaf respondents, references to identity were expressed in their need for role models. Their perception was that successful deaf people were more often oral, than culturally deaf. The dearth of public signing deaf people was thought to be wrong, as it constituted a public exhibition of weak deaf people. They expressed a need to identify with successful deaf people, who had a strong identity:

> I'll never forget, I went to a cathedral in the North, and saw Evelyn Glennie. She's deaf and I thought great! I expected her to sign, so when she finished her performance I thought I would approach her. My mother and father also thought she knew sign language. Do you know what happened? When she finished, she made a speech - it really hit me! I was annoyed at her. In my experience, famous deaf people like X, Y, and Z are all oral - where are the strong BSL people? Where?! ...Jack Ashley, Evelyn Glennie, David Bower are all famous deaf people around the world. They have no BSL, they are all oral. Doug Alker, the Chief Executive of the RNID - he was at the bottom of the ladder and he proved to everyone who thought that deaf people couldn't do it, by working his way to the top. He has not come from a well-off background and had shown that deaf people can do it, and at the same time he does not act proud of his job. (Sam, student)

The younger respondents were proud of their experiences of proving their identity and therefore of exhibiting their resilience:

> Oh my doctor had such an attitude problem. Once I asked him to refer me to a hospital - he said fine, and then went out of the room. I sneaked a look at my file. I realised that when I had gone to the hospital before the doctor was talking very animated to me - big mouth patterns. I said to him 'what are you talking about?' He looked surprised and said 'Oh, you can speak!' I asked him what he meant- he replied that it was nothing, but he thought that it was marvelous that I could speak. I found out, when I looked at my file that my doctor had called me deaf and dumb. I told my doctor off. The doctor said that I shouldn't have been reading his notes. I am not deaf and dumb, and he should have known better. He replied that he was sorry but it was the only way to describe me. I told him to put 'deaf with speech and proud'. (Lee, student)

A deaf identity, in a predominantly hearing society was considered a source of strength, with which to maintain wellness.

6.7.2.2 Identity as an aspect of culture

Identity was also portrayed as a vital aspect of deaf culture, something which, again, bonded members together. Rather than emerging as a necessity, it was perceived as a purely positive expression of culture:

> Identity is a question of shared experiences, experiences of oppression and so on, negative things and some of the more positive things, being on the same path, sharing the same community, empathising with each other. (Paul, professional)

> (I'd like to)...become a barrister or a lawyer. I wish there were more of them who are deaf. Maybe we could sit down and sign together - deaf power! Then hearing people would realise that we are equal to them. I have heard that there are some deaf lawyers in England, not just in America - they should start a membership club! (John, student)

Particularly within the student group, identity was celebrated against a perceived absence of identity in hearing peers:

> Recently I saw someone I hadn't seen for a long time, a hearing friend. I'd forgotten that a lot of people think that if you hug someone you're in love with them. So I hugged this person and she was so uncomfortable; deaf people really hug each other. Hearing people just say "hi!, you all right?" OK, the deaf way, well, another example, I left school and went to Derby. I met lots of new people. When I went home, I talked to my old hearing friends and they asked me how things were going in Derby, and I told them how I travelled round the country and met new people and they couldn't believe it. When I asked them how they were doing they had been doing exactly the same as before. They couldn't be bothered to travel, or meet other people, despite living in such a big hearing world! So I think that's what it's about; I love meeting new people but it seems like hearing people can't be bothered. It's the deaf way. 'I think that deaf people love meeting new people, whereas hearing people just stay with the same group. (Sam, student)

Identity was portrayed both as a tool with which to secure cultural affiliation, and as a continuing source of affiliation between those mutually identified as members of the community.

In summary, younger people were typically more eager to stress aspects of their experience of deafness which had bonded them as a group, and this very much corresponded to their stage of life. Younger people sought out experiences that

confirmed an emerging identity, and were less concerned with sustaining boundaries that served to exclude certain individuals.

In contrast, older deaf people, while acknowledging that they shared much in common with other culturally deaf people, stressed the skills necessary to cope with deafness. Many had experienced working life within the hearing world, and considered the biggest ongoing threat to wellness as the inability to cope with situations they perceived to be oppressive.

6.8 Conclusion

The views represented in this analysis of wellness clearly do not represent the views of all deaf people. Rather they maintain validity in seeking to represent the perceptions of two groups within the deaf community, who appear to have fairly strong views on what does or does not represent wellness behaviour.

Their interpretation of deaf wellness was often rooted in an understanding of what it was to be unwell. Perceived oppression from hearing people was often the instigation for the creation of a series of boundaries around those deemed well. Those in a position to experience wellness, did so, through distancing themselves conceptually from those they perceived to be unwell. This distinction was expressed in different ways. Those who coped, recognised their coping in part against those unable to cope. Insiders in the deaf community claimed this status through the recognition of outsiders within the community. The location of wellness is accepted as constituting all that lies within the boundaries, outside of which were located all those deaf people who were still seeking out wellness.

Most respondents were familiar with experiences earlier in life that represented being unwell, and these experiences were most strongly associated with isolation from others who were deaf. To this end, most respondents, both younger and older, discussed their lives in terms of a transition, of moving from situations of unhappiness to situations that promoted wellness.

The process of achieving wellness was thus essentially individual, in that each person had made a journey from what was metaphorically described as 'darkness to light'. However, while those from deaf families viewed this process as a smooth and natural development, for those from hearing families, the ultimate achievement of membership constituted a profound cultural shift.

The desire to be positively associated with other deaf people was discussed, as we have seen in two ways. Firstly, sustaining wellness was expressed in the maintenance of boundaries of those who could cope and those who could not, and secondly, through the affirmation of the characteristics of those who were well.

Throughout this analysis, the experiences of these cultural groups have been presented in isolation from any wider influence. Although reference was made to forces considered to be threatening, for example treatment by hearing professionals, discussion has predominantly focused on the *effects* of these influences on community beliefs rather than the process of influence.

Chapter 7 locates the deaf community in the context of hearing society, and questions the evolution of a minority culture in resistance to hearing majority culture.

Chapter 7: Study 4 - Contextualising the Construction of Deaf Wellness

7.1 Introduction

Chapter 6 explored deaf explanations of their community and personal wellness. Their accounts searched for the similarity in experience and behaviour that is the basis of deaf culture. As an indication of wellness, the data suggests that pathways to wellness are atypical and as a result, deaf people tend to still hold a legacy of oppressive belief in their own atypicality. Their descriptions are highly protective of their own culture and experience and by describing events and responding to case studies, they identify parameters of normality in their community. This chapter explores one source of the comparative wellness judgements – the professionals who served as the bridge to the hearing community.

This chapter will consider the belief systems of a sample of hearing professionals, examining their possible influence on the deaf construction of wellness. The aims of Study 4 were thus twofold; firstly to consider the belief system of a group of hearing professionals working with deaf people and secondly to describe the environment within which deaf people developed perceptions both about themselves and about their own experience of wellness.

7.2 Respondents

Interviews took place with 16 hearing people who had been or were currently employed in the field of social welfare with deaf people in different parts of England.

Six respondents (five men and one woman) had been working for at least fifteen years in the field; many for far longer. Most had been trained by missioners to the deaf (see section 1.1.1) but were themselves described as 'welfare workers for the deaf' during the earliest part of their professional lives and 'social workers' during the latter part. The work of welfare worker emerged from that of the missioner although reflected certain changes in the professional style of work. None of those interviewed were currently involved in professional social work.

The remaining ten respondents (six women and four men) were employed either as social workers or as residential social workers with deaf people. Each had been working for at least five years and approximately half of this group had been trained by welfare workers for the deaf.

Throughout this chapter, for reasons of simplicity, the term 'welfare worker' will be used to describe the first group of respondents, and the term 'social worker' to describe the second group.

7.3 Procedure (March - April 1996, May - June 1996)

Initial contact was made by the researcher who explained that the interview would be investigating respondents' knowledge of and experiences with deaf people, particularly within the context of mental health. Interviews took place with each respondent individually and usually in their own home or workplace. A structured open-response interview format (section 3.22.1) was chosen to allow flexibility in response while maintaining some uniformity across all the interviews. An interview schedule can be found in Appendix 10

7.4 Analysis Procedure

As all respondents were hearing, interviews took place in English. Each interview was recorded on audio-tape and later transcribed. Transcriptions of interviews were sorted using 'The Ethnograph' software (section 3.25).

7.5 Contextualising the Construction of Deaf Wellness

An account of the relationship between hearing professionals and members of the deaf community will be presented in three stages:

1) The relationship will be located in a social and historical context.

2) The power held by these professionals will be examined from different perspectives.

3) Hearing professionals' beliefs will be outlined both with reference to the nature of their professional role and to their beliefs about deaf people in general.

Throughout the analysis, respondents' names have been changed to protect anonymity.

7.6 The Relationship between Deaf People and Hearing Professionals in a Social Care Context

Social workers, teachers of the deaf and medical professionals were introduced by respondents in Study 3 (Chapter 6) as being of significance to deaf people. Each professional group could be described as reflecting different aspects of the majority (hearing) culture.

While many predominantly hearing professional groups could be described as being in a powerful position in relation to the deaf people they worked with, those professionals involved in social welfare with deaf people were arguably the most powerful. Traditionally the relationship between deaf people and social welfare workers has been extraordinary (see section 1.1.1), and in its power quite unlike the relationships which existed between deaf people and any other professional group. The reason for this phenomenon will now be considered.

7.6.1 Cultural heritage of welfare work

Respondents were aware that social welfare work with deaf people carried a huge cultural heritage within the deaf community, built upon on a strong base of religious philanthropy. 'Saving souls' in a religious sense added to the need to satisfy public sympathy for deaf people. The Church's responsibility for the welfare of deaf people ceased in 1963 (section 1.1.1). Nevertheless, former welfare workers gave the impression that the spirit of evangelism, which had traditionally fuelled welfare work, constituted a significant component of the professional culture for many years afterwards.

Welfare workers stood apart from other professionals in their *style* of work. Unlike welfare workers with hearing people, most older respondents described living "above the deaf club". Inheriting responsibility to nurture, both spiritually and pastorally, the deaf

people in their care necessitated being on call at all times. Respondents suggest that this arrangement created a particular relationship with deaf people.

7.7 Welfare Worker's Power

Without doubt the relationship between welfare workers and deaf people was immensely powerful. Before considering specific aspects of this power, the following section presents references to their power, as it was perceived by respondents:

> I mean back in the 1960s you were almost like a Catholic priest, your word was law. I remember going to a rally and there were about a thousand deaf people there and a fight broke out. You only had to sign that you were a missioner... Now do that, and you're the first one to get punched! I remember going into these things and you might be pounding away in your heart but you really felt that you carried this authority and status, not that I was a bossy pants but... (Alan, former welfare worker).
>
> I mean some of them were authoritarian and dictatorial, compassionate...call it what you will but they had a tremendous power and, if you wished, some of them ran deaf people's lives. (Jack, former welfare worker)

Throughout interviews with welfare workers, situations were recounted which confirmed this powerful status:

> For example, we went to X and started doing group work. We talked about problems and I remember this time we were in a circle and I told them that next week they should put the chairs like that. When I came in they had put the chairs in a horse shoe with one in the middle, and it was obvious that's where they wanted *me* to sit. When I first started doing group work I found that what I had to do was keep throwing it back because they'd been so used to "HEARING CLEVER DEAF STUPID. YOU KNOW BEST YOU TELL ME. YOU SOCIAL WORKER YOU TELL ME".[19] There was a lot of this because they had been used to being told what to do. This is where the power of the welfare officers came from but in many ways it was easier...for six weeks I came into the group and eventually they got it...it was to do with their perception of this person who is hearing, a social worker or a missioner or whatever, and he knows how to help deaf people - he was powerful. (Dick, former welfare worker)

Subsequent generations of social workers reported being treated as powerful, and were aware that they had *inherited* this professional status:

> For those that use social services and maybe have done all their lives, there's no limit to what the social worker can do. (Julian, social worker)

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[19]The use of upper case in direct quotations denotes the glossing of sign language into written English.

The following section suggests three explanations for the power of this professional group. The first explanation is based upon their knowledge of the language of the deaf community - sign language. The second is based upon their presumed knowledge of deaf people. The third explanation considers their role as arbitrator or bridge between deaf and hearing worlds.

7.7.1 Power through knowledge of sign language

One of the most significant skills of welfare workers and social workers was knowledge of sign language. Before the introduction of professional BSL/English interpreters, welfare workers and social workers were the only professional group thought able to communicate with signing deaf people.

Older welfare workers described a rigorous and intensive training, most often from their predecessor, the missioner, in the acquisition of sign language. All former welfare workers interviewed, claimed fluency in sign language. Social workers' responses were more varied. Several felt confident in their ability to communicate in sign language, while others felt less fluent.

Their special abilities in communicating with deaf people left the welfare worker highly revered, as the following examples illuminate:

> People being what they are, like it or not, when human beings are out in a position where they are made to feel important, they respond to that and take on that mantle of king as it were. I think social workers did, not only because of deaf people but people in the community generally. They would go to a talk and see this man who was magic with his hands and say "Oh isn't he clever, it's marvellous" or whatever so sadly that had an effect on their perceptions of their own power. They had a tremendous amount of power because they were the link with the hearing world and everyone including deaf people gave them that authority. (Dick, former welfare worker)

> ...the one thing that is very significant in the deaf community that doesn't apply to other groups is the power that came from the missioners and the reason they had a huge amount of power was the segregation of the deaf community because of the inaccessibility of the language. The missioner had access, so he or she had power as a provider and gatekeeper to services - that was a very powerful position and it would be easy for people knowingly or unknowingly to abuse that because people from the outside could not perceive what was going on because they had no access to the language. (Fred, former welfare worker)

As a result of this knowledge, within the deaf community welfare work evolved around the welfare worker's role as interpreter. Several situations were described in which the ability to understand sign language awarded welfare workers a somewhat elevated though certainly not unwanted status. For example Alan recounted a situation in which he had intervened between a young deaf woman and her mother. He perceived his knowledge both of the deaf community and of sign language to have left him better able to make judgements with regard to the welfare of the woman than her mother was able to do:

> ...she was signing away and her mum said "I knew she signed but I didn't realise she finger-spelled", and I said "she doesn't - do you want me to tell you what she is saying?- hjhskskshshsgsskssyst, gobbledegook", she was away with the fairies. Someone else might have thought she was OK but she wasn't and needed instant help...I've been in situations where your presence has prevented someone from being admitted but also when you have admitted someone. There were cases when the doctor turned up and took the mother's word for it before either myself or one of the other duty teams arrived. They can use the Mental Health Act to get their son who is just a bad bugger out of the house. (Alan, former welfare worker)

These situations were by no means exclusive to welfare workers. Many social workers described the relationship they had with clients, concluding that their status within the deaf community was determined partly by their degree of fluency in sign language, and partly by their ability to interpret:

> The people who come regularly they know us...we are around, we aren't just there as social workers, we tend to get to know them. At some point you've interpreted for their weddings, so you're much more involved. I mean things will change and we won't be doing that sort of thing, but this chap...honestly, I had interpreted at his wedding and then they end up having a family and you're there for the GP visits and school meetings and so on, so I know him well. (Dawn, social worker)

The feeling that they were 'falling short' professionally perturbed those who did not feel their signing matched the levels of their predecessors. Two thirds of those interviewed in the social work group felt that their level of signing was inadequate and many reported feeling they were not meeting their clients needs. One person reported feeling "desperately helpless" when she was unable to communicate adequately in sign language with someone who had arrived in a distressed state, seeking her help:

> We're so slow, you know they'll be signing and we finally get one word out and they'll say "I know, I know!", so we improvise. Our signing is inadequate but we use every kind of way. We act things out or write, sign whatever we can - we make up signs. We find that whoever we work with you have to do that. (Eve, social worker)

The absence of sign language skills distorted the power base upon which the profession traditionally operated. While many of the newer social workers were optimistic about changes that lessened this expression of power, there was still uncertainty as to the nature of a different professional relationship. This uncertainty was tied to the belief both in longstanding deaf cultural attitudes and in the existence of an equally strong hearing professional culture.

7.7.3 The good shepherd who knew his sheep

Within the welfare worker group many spoke as if they knew deaf people almost better than deaf people knew themselves. Many leant heavily upon the knowledge that the missioners had been instructed by their predecessors to make it their mission to acquire this knowledge of deaf people. One or two respondents drew upon the well-known metaphor of the missioner consequently knowing his charges, as a shepherd knew his sheep:

> I remember being lectured by the late X missioner, a very well respected chap, and one of his lectures was "a good shepherd knows his sheep", which meant that a good missioner knew the group of people with which he worked, inside out. (Jack, former welfare worker)

There was a general consensus among those interviewed that their work demanded this depth of familiarity. Consequently many claimed to be able to assess whether a deaf person's behaviour was normal or abnormal.

> We had a deaf fellow who, when he was excited went [groans] but when he upset went [groans slightly differently]. That is the difference between happiness and anger and you knew that on the basis of experience, but to someone who doesn't know it, it sounds like anger, mania even. Other's think "this bloke is a bloody nutcase, we'll have him in"...(Jack, former welfare worker)

None of those interviewed claimed to have experienced any situations in which their judgement had been challenged, for example:

> ...the social worker carting someone off and the deaf community objecting...I don't think that has happened here. (Don, former welfare worker)

Whether welfare workers were actually advocating for deaf people or whether in pursuit of advocacy they nevertheless misunderstood deaf people, is hard to ascertain. Certainly they believed that their interpretation of behaviour constituted an insider's perspective. They also believed that their assessment represented a professional or educated interpretation of what deaf people themselves would perceive:

> I think it would be hard to prove one way or another whether missioners, by and large, acted as advocates in that situation and did their best to prevent unjustified admission by a doctor, or whether their own perception of deaf behaviour was such that they saw it as abnormal and concurred with the doctors view, I honestly don't know. (Fred, former welfare worker)

> I think they would rely on their own knowledge of an individual and their own personal understanding of what mental illness was for deaf people. I think a missioner who knew, as they often did, members of the deaf community very well might in a particular case say no this person is not mentally ill, his behaviour is explicable in terms of him being a deaf person, rather than seeing symptoms of mental illness. I could speculate that the better amongst them might have been advocates for those deaf people when suspicions were that this person might be mentally ill. I would expect the missioners to advocate the opposite view based on their knowledge of the individual, because it would often come down to an interpretation of behaviour which due to deafness might be rational and reasonable. (Fred, former welfare worker)

Within this caring, and yet ultimately controlling framework, welfare work often extended to making decisions *for* deaf people. For example, in one account a welfare worker decided which deaf people in his care would be allowed to go to the social night at the deaf club, based on their behaviour and the individual's perceived acceptability to other deaf people. In another case, the social worker uses his knowledge of the community, and power, to orchestrate the reintroduction of an excluded deaf club member:

> They shut him out, they do it wonderfully, they put the barrier up, he gets the message and never comes in here again except on Thursday morning when I'm doing the coffee. We end up with three or four deaf middle aged men who are outside the deaf community. They come here for a cup of coffee and we might go off to a museum or something and its all with hopes of integrating them back into the deaf community again. (Julian, social worker)

There was agreement that many welfare workers operated within a paternalistic framework and that in many ways this style of work represented the prevailing professional culture. In retrospect concern was voiced that this type of professional control, especially concerning activities within the community, had been inappropriate. as the following example illustrates:

> What we were doing in many ways was saying that deaf people in the community had a moral responsibility to do something for the poor deaf people that were here, and yet when you look at it realistically I think there's something wrong with that argument somehow. (Dick, former welfare worker)

Within the group of social workers, far fewer made claims to intrinsically understand deaf people. Many had had substantial experience in other fields of social work and reported feeling ill equipped to assess deaf people's language or behaviour:

> My skills aren't good enough, I would have to check out with somebody else, you know "did they really say that?" If someone said to me "I'm very depressed, I didn't get out of bed all weekend" - that kind of stuff, then that would be OK. But someone had dementia and it took a long while to pick up that that was what was going on. (Alice, social worker)

In these situations social workers also reported identifying other deaf people in the community who could better advise as to the well-being of other deaf people, as they felt unqualified to do so:

> X is quite good at directing people or giving us the nod and the wink so we can approach people. He did it with one chap who eventually came in and he was quite fidgety and the next time he came in he was much worse and he wasn't right, fidgety and making noises. I asked him if he would like support and he said he would like support (Dawn, social worker)

In conclusion, the relationship between these welfare workers and deaf people contained strong elements of paternalism. Testimonies suggested that former welfare workers in particular, fostered relationships with deaf people which, at times, were highly controlling. These relationships were based on a very real belief that they were the only professional group who understood and were able to communicate with deaf people. While many social workers questioned the possibility of insider knowledge of deaf people and certainly questioned any desire to sustain this type of relationship, nevertheless, there

was recognition that this knowledge constituted power, and that this power had sustained professional practice for many generations.

7.7.2 Power as bridge between deaf and hearing

The second source of power was in the welfare worker's role as a bridge between deaf and hearing worlds. Accounts illuminated several different aspects of this mediating role. As a bridge between deaf and hearing people the welfare worker consequently had enormous control over the perceptions each group had of the other. In terms of language, he or she was not only the vital translator but through this communication disseminated knowledge of deafness to the outside world:

> So you go and see the GP and the GP probably meets maybe four deaf people in his lifetime and you have to go and try and persuade this GP who hasn't the knowledge that you have that you have more knowledge than he has, I mean straight - away his ego is affected, "I know all about this guy, he doesn't need an interpreter, we can manage with paper and pencil". So all of a sudden the poor old missioner is on the defensive and in a conflict situation when all you want is some service for this individual who you have some concern for. (Jack, former welfare worker)

Likewise the following account describes a social worker setting up a situation which ultimately would demonstrate deaf people's experience to an outside agency:

> We had the woman down from the DLA[20] and I said that I would be with her in a minute and I left her there for two minutes with deaf people in the club. The deaf people knew who she was and they didn't half give her a hard time and when I got out there she was like "help help!" I said to her, "this is how deaf people feel, but not just for ten minutes, for all day everyday". The only way is to take them to the deaf club and let them try and order a drink and ask where the toilets are. (Julian, social worker)

The welfare worker's knowledge both of sign language and of deaf people, ensured that other professional groups operated primarily through them:

> If the social worker thinks something is amiss he'll say so. If he thinks he needs some more help then he'll do it in some other way, whereas with an interpreter they'll interpret and that's it. I think there is a little bit more assurance having us there. There are certain cases where I'll go to the doctor with people rather than the interpreter. That may be where maybe they aren't understanding how to take the medication. An interpreter would put across how they take it, but they may not be too sure. If I go along I can follow that

[20]Disabled Living Allowance (Social Security Benefit).

> up and make sure that the medication gets taken properly. There is a little more support there. A professional interpreter would go there, aid communication and then leave. Deaf people want more than that. (Julian, social worker)
>
> I think there are obviously problems in communicating their needs to other people and the skill of the social worker is in identifying those needs which probably wouldn't be done by the generic social worker. (Don, former welfare worker)

A powerful situation clearly emerged in which welfare workers perceived themselves, rather than deaf people, to be gatekeepers to the deaf community.

Similarly, as professionals arbitrated between deaf people and outside agencies, so too the outside world was often brought to the deaf community, through the welfare worker:

> The gap between hearing and deaf was there, like two different levels. It meant trying to reconcile two levels of thought and education, you know, so the missioner was placed in a position of extreme trust. He was a friend, welcomed more often than not, OK sometimes he was shown the door but you were often the messenger of bad news and they often threw out the messenger as well but it was what you were. You were respected because you had more knowledge than they had. If you didn't know you would find out for them. (Jack, former welfare worker)

Information being passed through the welfare worker was inevitably interpreted with some subjectivity:

> If you are a controlling person, yes, you can control and censor all the information that goes out and comes back. (Laura, social worker)

As long as welfare workers claimed to be "experts in deaf people" (Don, former welfare worker), they were able to justify taking responsibility and ultimately power:

> ...there was an understanding that the welfare officer would look after the deaf. It was a 'looking after'. Sometimes it was easier to be looked after because if you think about it they had a pretty rough time from an employment point of view, and from an educational point of view, you know, they were isolated from the community. The fact that this man, this wonderful man, called the welfare officer would look after them, was great. He was the guy who would chase round trying to find them a job. He was the guy who would arrange socials for them. He was the guy who would interpret when they were in trouble. He was the guy who would act as the probation officer, so he was the God. It was understandable that they accepted that. (Dick, former welfare worker)

They perceived themselves to be "the link, the contact, someone who could make things tick for deaf people" (Dick, former welfare worker).

7.8 Welfare Worker's Beliefs about Deaf People

A significant component of the relationship between deaf people and hearing professionals concerned the strong beliefs held by hearing professionals of deaf people.

Three stages of a belief system can be identified. In the first instance deafness was presented as a devastating handicap. The second stage concerns beliefs that pathologised the deaf person, blaming deafness rather than society for deaf people's underachievement. The third stage in this system justifies a particular style of welfare work, based on beliefs about deaf people. Each stage will be examined in turn.

7.8.1 Deafness as a devastating handicap

Particularly for welfare workers, deafness was portrayed, at least as an unfortunate affliction and at worst a "devastating handicap":

> It really is an extremely devastating handicap. I think of all of them it's the worst. I'm sorry I do...Sometimes your mind races through all kinds of avenues and why is that?..because you have thinking power. You are talking about a group of people who've never had that advantage. It's a bloody awful handicap...so for all they're born deaf, but they're totally unaware of their handicap.until they're aware of what they're missing, how can they do anything about it? ...it was this philosophy that is so very difficult for people to comprehend that they aren't just hearing people who cannot hear but they're hearing people who've never heard at all and it's so totally different. (Jack, former welfare worker)

Descriptions of deafness leaned heavily towards a deficiency model of disability. That is, the lack of hearing constituted a significant departure from the normal, a severe deficiency. As a result many respondents focused predominantly on situations which were inaccessible to deaf people, such as "hearing the birds sing":

> I think one of the things deaf people miss is music and they won't get the same enjoyment from music. I've thought about that because I enjoy music...people talk about bird song - I mean it's the clues about sound. How many sounds do you hear between getting up and going to work? They are clues that you take forgranted. (Don, former welfare worker)

Such responses incorporated, to varying degrees, a sense of genuine tragedy in the handicap of deafness, which again had the effect of justifying the professional nurturing of deaf people.

7.8.2 Pathologising deaf people

Among former welfare workers, deafness itself was described as having a devastating effect on development. The following explanations were given as to the effects of deafness:

> I remember giving a talk to some women many years ago and there was a deaf lady who had come to listen to me talk, and she had a hearing daughter of about five and this deaf woman was in the audience and after the talk, I mean these women obviously knew the little girl, a precocious little thing and said 'get her to sing!', so this kid sang at the front. The deaf woman then said to me 'what does she sound like?'...She was a deaf woman among about thirty or so hearing women. I think that in itself is a lesson about deaf psychology because I then spent another half an hour with these women talking about this and I said 'you know she will never hear her child laugh or cry' and when you think of the effect that that has on our development. I mean listening to someone cry. Deaf people don't get any of that and that must have an effect on personality development. (Dick, former welfare worker)

> If you think of the handicap of blindness which is a dreadful one, I mean every handicap is dreadful in it's own way but we can conceptualise blindness by shutting our eyes and imagining what it must be like. It's easy perhaps to do that. If you sit on one hand and try to button your shirt or do up your bra or whatever you get some idea of what different handicaps must be like...you know, you can get someone to push you around in a wheelchair but there is no way you can pretend to be deaf, because we would be deaf from a power base of now. If you went deaf tomorrow you would still have that experience of hearing to help you go on. This is the concept that's difficult to get through to people. We aren't talking about someone who's deaf now but about someone who's never heard at all...can you imagine what it's like never to have heard and to try and learn language? (Jack, former welfare worker)

While deafness was thought to create fixed ceilings on levels of independence, the need be taken care of was justified. As intermediaries between deaf and hearing worlds, the pathologising of the deaf person, justified this style of welfare to the outside world.

Of great significance is the fact that a construction emerges of 'deaf normality'. In other examples, more specific traits, strongly reminiscent of the deaf personality (section 2.2.1), were ascribed to individuals, again by virtue of deafness alone. For example deaf people were portrayed as being more egocentric than hearing people:

> Teenage is a critical age, when the care of others starts to come into it. That's' when the deaf child starts to fall miles behind. Suddenly there is a focus on the "me me me" bit which is deafness, in many ways, whereas hearing kids will mainly start to become aware of other people's needs. It's trying to develop that bit which is a long way behind. I

> mean you only have to go into conversation and they can't wait to get onto them and then someone else comes in and they aren't bothered that this person might have a crucial bit. They want to talk about their bit, it's locked in. (Alan, former welfare worker)

...or selfish:

> Maybe it's the age group, but they aren't bothered what happens to other people, they're very selfish people. (Brian, social worker)

Deaf people were described variously as immature, suspicious, or as the example below suggests, as having low expectations:

> Some deaf people have very mundane little lives but they are totally happy. They have very low expectations. You can maybe show them other things but maybe they'll get depressed because they can't reach these levels, I don't know. (Dawn, social worker)

In both groups of respondents, one trait emerged more frequently in descriptions of deaf people than any other; that is, the belief that deaf people were limited to black and white thinking. Beliefs about concrete thinking and fundamental differences in cognition between deaf and hearing people were found both in welfare workers and social workers to the same degree.

Four respondents specifically referred to black and white thinking as a serious limitation, resulting in deaf people being "rigid in their views and perceptions" (Sam, social worker). While one social worker viewed this as a direct result of being "ill-educated" (Sam, social worker), others believed it was a result of the limitations of sign language, as black and white thinking was reported to occur in those of deaf families who had higher language levels:

> Sometimes when someone was trying to decide what should happen about a certain incident, or whatever, his view may be harsh compared to other people. Maybe that's his black and white way of looking at things which deaf people tend to do, there's not so much of a grey area...I think when hearing people have problems they can grasp abstract ideas and concepts and I think that's something generally that deaf people don't tend to do so much. I am generalising again but in my experience they tend to do it this way more than that, because that's probably the way things have been explained to them. When you're trying to put things over maybe in BSL, it's probably been explained in black and white terms. So their ideas, as they grow and build with that language, are limited by a bit of a black and white language. That's my personal opinion. If people offering sign language were prepared to go into detail in early life then maybe they would

grasp a few more abstract ideas, but it's difficult to put abstract ideas into sign language, isn't it? (Sam, social worker).

I know some people will say there's no such thing as an average deaf person but the type of person I used to work with would not have the capacity for wide thinking. It's this black and white, positive negative thing. Something is either black or white, there are no shades of grey. Your average deaf person thinks in that manner. When you think about it, when you have the ability to reason you can put all shades of grey into something, because you can see from all sides. You listen to someone else and where they're coming from and you think "Oh, I never thought of that". When you think, your mind is racing through all kinds of avenues and why is that...because you have thinking power! You are talking about a group of people who have not had that advantage. It's a bloody awful handicap, you know. A deaf person is intelligent but how can you...I mean you need language to be able to grapple with concepts and thoughts, don't you? (Jack, former welfare worker)

As a consequence deaf people were thought to have only a basic understanding of emotions and to have restricted themselves in their inability to take a centre line.

> There are some horrendous right-wing statements in a deaf club, you know "build the gallows!"- some of the black and white thinking is horrendous. (Alan, former welfare worker)

While particularly social workers could trace the root of some collective traits to education or to experiences in childhood, the general impression was again that such traits constituted part of a deaf personality, and as such were relatively unchanging.

7.8.4 Justifying a particular style of welfare work

Beliefs about deaf people were rarely 'checked out' with deaf people themselves nor with other professional groups. The effect was to create a relatively closed belief system, which was supported by interaction among welfare workers.

A closed belief system also resulted from hearing professionals positioning themselves as cultural insiders. Assuming responsibility both for protecting the interests of deaf people and bridging gaps in awareness between deaf and hearing worlds, appeared to necessitate assuming this insider status within the deaf community. This was most clearly witnessed in reports of welfare worker's alienation from other professional groups, such as teachers of the deaf or the medical professionals, designated cultural outsiders by hearing professionals:

There was a deaf man who lived out at X and I knew that he had behaviour characteristics that were abnormal, and I wrote to his GP expressing my concern and he said "rubbish, he's all right, I know him, no problem!" I was extremely concerned so I wrote to the chief mental welfare officer expressing my concern and I wrote to the principle officer for this parish. I put my rationale behind me, because this man had been an intelligent deaf person...I believe he was the first deaf person in X not only to own a car but to be able to repair a car. All of a sudden this person was gibbering, he was abnormal in his behaviour and the GP refused to accept it. He was found in a collapsed state, his house was a hovel, it was filthy and disgusting but it was also his mannerisms, the way he dressed and talked, you knew there was something wrong. On New Year's morning he was found in a collapsed state on his doorstep. He was taken to the local hospital and there I met the GP and I still expressed my concern and he still told me I was talking a load of rubbish. It wasn't until this deaf man started to roll his faeces into balls and flick them at people that the GP said yes there is something wrong. He got him referred to John Denmark and he was diagnosed as paranoid schizophrenic. (Jack, former welfare worker)

In another account the parents of deaf children had asked advice from the welfare worker as to how they could learn to communicate with their child:

> "Can you tell me where I can learn to talk to my son, but don't tell the headmaster because he doesn't agree with it". That was wicked I think. (Dick, former welfare worker)

Though the question above is straightforward in it's simplicity, it illuminated different aspects of the relationship involved. The parent sought advice from the welfare worker on how to communicate with their own child, implying that the welfare worker's relationship with the child was at least more communicative, if not closer than the parent's. The welfare worker was also expected to be allied more closely with the deaf person and their family than were other professional bodies, such as the school.

Welfare workers were aware, and at times appeared to revel in the knowledge that their position was envied, often marvelled and certainly unparalleled in other fields.

> ...it's not just asking the question "are you all right?" it's asking the supplementaries and getting the slight subtleties when they come back. It's like the way you and I are talking now, being able to say "what do you mean by that?" being able to clarify it or explain even deeper. (Jack, former welfare worker)

> ...lot's of deaf people used to say "it was better before, better before". That was only because of the communication, remember the missioner could communicate, he knew the A-Z and the subtleties and then suddenly this social worker with their CQSW or Ph.D. or whatever was thrust upon them but couldn't talk to them. (Jack, former welfare worker)

As we have witnessed, the definition of cultural insiders differed significantly between hearing professionals and deaf people (Chapter 6). To deaf people, hearing professionals were ultimately outsiders, though they often knew deaf people and their language well. A difference emerged between social workers and welfare workers with respect to any insider status. Welfare workers justified their high level of involvement by claiming to understand the language and behaviour of deaf people from inside the community:

> ...what you are talking about is a group of people who because of their hearing loss from birth did not have the breadth of knowledge and education that their hearing counterparts did, their attitude to life was coloured by this deprivation. Therefore your missioner and his wife more often than not...were responsible for...well if you think of deaf people as being a microcosm of society...all the complaints of society. Your missioner had to cope with that so that was work education, social sexual, marital, raising finance, preaching, trying to persuade people to be philanthropic and give a deaf person a job, explaining to a GP why they had to interpret...a whole host of tasks...I mean I could go on for hours...were often regarded as way out. I don't know if you ever heard of a record by Peter Cooke. There was a pseudo-interview about trying to teach a blackbird how to swim under water. Quite often we were looked upon in the same kind of ilk. We were doing something kind of obscure, they were looked upon as the parson's frolic. (Jack, former welfare worker)

Social workers, on the other hand, reflecting current approaches within the wider social work field, more often claimed outsider status, relying on other deaf people to judge normal and abnormal behaviour. While they sustained certain beliefs about deaf people, there was creeping recognition that their observations were valid only from an outsider perspective.

7.9 Resistance from Deaf People

In Chapters 5 and 6, deaf wellness is reported to incorporate the recognition and rejection of oppression from hearing professionals. Certainly, the accounts of deaf people themselves (Chapter 6), highlight the fact that the views of welfare workers often contradicted those of deaf people. Nevertheless, the influence and control of hearing professionals has clearly been enormous.

Two explanations emerged for the perpetuation of the oppressive aspects of the relationship between deaf people and welfare workers. The first concerns both the

relationship between deaf people and welfare workers in a wider societal context, and welfare worker's beliefs about deaf people. The second explanation considers the strength of internalised oppression among deaf people and subsequent dependency on hearing professionals.

7.9.1 Barriers to change in social structure and belief systems

Sections 7.6, 7.7 and 7.8 suggest that the powerful nature of the relationship between hearing welfare professionals and deaf people was reinforced by two factors. Firstly, by the unique position of the welfare worker constituting a bridge between deaf and hearing worlds, and secondly, through collective professional beliefs about deaf people.

Clearly relatively inflexible societal structures referred to earlier, reinforced the strength of the relationship between deaf people and hearing professionals. While the welfare worker sustained a role as mediator and protector, change and transition, at deaf people's initiation was difficult, and at the initiation of the professional, unlikely. For example, in defence of not hiring deaf residential social workers, a move that symbolised a positive change in line with practices in other fields, one respondent replied:

> ...at the end of the day what you've got to realise is that Local Authorites or someone is paying a lot of money for someone to come here, and what you have to do first and foremost is say that I have a moral obligation to the client, to the deaf person who is coming here and to the person who is paying the money. The second thing is to say that what we ought to do is get more deaf staff in. Well that's fine if they can do the job, whether they are deaf or hearing...if I was boss and I took on staff who were not really able to fulfil the job, who I thought because they were deaf ought to work here. I mean it's a bit like if I go to buy a suit of clothes in a shop and the manager said, "Well, I've made your suit, it's not quite right because I took on a bloke I felt sorry for and I felt he ought to start". So you're paying the same money but it isn't as good a suit...we do have a responsibility but I don't feel that people who are receiving the service should suffer while it's happening. (Dick, former welfare worker)

Clearly in this example any inflexibility resulting from the welfare worker's role as mediator is matched by similarly rigid beliefs about deaf people's actual competency. Their powerful position clearly limited the strategies with which they could make changes in the nature of the relationship, should they wish to.

While recognising the need for change, there was also a reluctance to relinquish control of the process. The following account describes a welfare worker attempting to encourage a sense of responsibility among deaf people:

> One of them had his jacket had got torn. He explained that he had been going off somewhere and he had asked this lad to look after his jacket. He'd gone off and the jacket had got torn. And I said "fine", and we set up a court scene with someone defending him and someone prosecuting him and someone in the chair. The consequence was that "he's guilty and will have to get me a new jacket". That was their opinion. Then I said "OK lets start to bring in the defense". I asked "Did he have the right to tell someone to look after his jacket?" Could he have said "Do you mind looking after it?" So if he hasn't accepted, is he responsible? And they weren't so sure and uncertainty starts to come in and there are a whole lot of other things there. We got to the end and I asked what they thought should happen now and it was 50:50 really, but we'd gone through that process. (Alan, former welfare worker)

Throughout the mock judicial exercise the welfare worker had nevertheless remained judge. Similarly the following account describes the carefully controlled process of handing over responsibility for management of the deaf club, to deaf people, a process which took over twelve years:

> ...we made quite good progress and in the end we were training them, so if we met on Tuesday we were training them on Friday and getting their case together, you know "What do you want to say, who's going to say it, is it going to be just one spokesman all the time?" and passing it around so that different people were coming to support them, so we were teaching them tactics really. That went on for some time. It stopped about three years ago but it went on for about 12 years. That's led onto our new structure which has deaf representatives on it and they're full trustees in their own right...but that's classic because we've just become a company, and the vice chair who has always been shouting off about wanting to be a trustee, they had a meeting and of course they had to discuss business, from the finance and income generation and expenditure to targets and contracts and he sat there yawning and saying "this is really boring". So I said "what do you want to talk about?" and he said "I want to know why the young people are using the billiard table?" I said to him "Do you really think this committee is to do that, I mean would you bring that very important issue in front of a board of trustees?" He withdrew and didn't come anymore. (Alan, former welfare worker)

In other situations social workers, with no preparation, simply arranged for deaf people to take their place. Progress was envisaged through the creation of situations in which deaf people imitated hearing professionals, for example, in learning the protocol in order to nominally sit in on committee meetings:

> I want to get them on to these committees and let them influence decision-making. With the hospitals becoming Trusts there was a big AGM and we really ferried the people there and encouraged them and dragged them along kicking and screaming. If you want the hospitals to improve their services and to get minicoms and employ interpreters, get in there and say "what services do you offer deaf people?" (Dawn, social worker)

As we have witnessed, beliefs about deaf people were also used to justify their incompetence in taking control:

> The gap between hearing and deaf is like two different levels. It means trying to reconcile two different levels of thought and education...we were having difficulties with one committee and I remember this one deaf fellow who was very well respected trying to explain, breaking things down into the simplest form, but they still couldn't understand. So you have the different levels of competence within the deaf community as well. Two-year-olds should have been able to understand the way this bloke was explaining things, he was so facial and expressive but they still couldn't understand it. But now, all of a sudden you're getting deaf people who are able to accept responsibility. I mean of course for all the ones that can, there are nine that can't. It's then left with those that can, to take on *all* the responsibility...it's like anything, you can say that the way forward is to get more deaf people into positions of power, but until they're capable of accepting that responsibility... (Jack, former welfare worker)

> ...the TV and other things have created an elite of deaf people, but you still have those people right on the floor, some have uplifted themselves but there is still a group on the bottom who have problems finding jobs or who have jobs that don't really stretch them. There's always a group of people who will require our help in one way or another. (Don, former welfare worker)

While these attitudes were predominantly found in former welfare workers, there was a strong sense in which the inheritance of working practices by social workers, at times, extended to the inheritance of a professional culture and associated belief systems:

> I mean once a certain kind of dependency has developed, it's hard to break the mould. I mean if you take the social worker away, how do they then find out about those specific things, you know checking they've filled in forms right? The times I've visited the deaf club before, and there are quite a clambering of people with different types of problems, mundane problems and stuff like that but they need to see someone about it (Brian, social worker)

> If a deaf person came in, in the morning, if it was feasible then I would ask them to come back in the afternoon. Very often it was "I've got water leaking from somewhere' or 'I don't feel great, I want to see a doctor". You could tell them to come back tomorrow but it's often just a case of making a phone call or explaining letters or whatever. It's normally quite straightforward, whereas the alternative was for them to trek back in the morning or whatever so often I would just make a phone call or explain the letter. Or of course they could go to a neighbour or another member of the family, but I don't feel that

> deaf people should have to go showing their business to the neighbours or get them to call the doctors for them. They have their right to privacy the same as everyone else. The only way to do things privately is to do them here. (Julian, social worker)

Accounts of welfare workers attempts to relinquish control appeared to actually reinforce their power status. Change, to a large extent was controlled by professionals and sought to feed off the very structures and beliefs that have effectively sustained a powerful relationship for generations. In this way 'deafness' was contained, away from the public domain.

Clearly, such a situation allowed little potential for deaf people to acknowledge their own self-image or perceptions of wellness.

7.9.2 The existence of internalised oppression

A strong view particularly among social workers was that deaf people had not knowingly accepted or agreed to the welfare worker's power. Rather, respondents were aware that their power, and at times oppression, as a professional force had been *internalised* to the extent that any resistance was extremely difficult. Consequently, many examples were given of situations that appeared both to invite and also to confirm a dependent relationship:

> It's partly tradition, I mean the sign for social worker is still the sign for missioner...but many people won't use the interpreting service for hospital appointments. They go with the chaplain, even now. I was amazed the other day because I was requested to go along to a hospital appointment because the chaplain couldn't go and they don't want interpreters...they are based out in the country and they have less control over them, they know the chaplain is based here and comes from the tradition. (Julian, social worker)

In one account, a capable man, on receiving his housing benefit form had filled the correct answers in on a piece of paper. Having had it checked by the social worker he still refused to fill in the answers himself in pen, believing only the welfare worker was capable of doing the job correctly.

Other testimonies suggested that the situation was changing and that both hearing professionals and deaf people were now much more aware of the situation, thus leaving them in a better position to resist oppressive structures. The following account while

illustrating the cultural transmission of internalised oppression within the deaf community, is presented hand in hand with a report of very real resistance:

> I remember one meeting here. We were looking at the way we were and what we were doing and so on. One man stood up, he was about 18 and both his parents were deaf, and he slagged off what we had got at the moment saying that the missioner, Mr.X, my predecessor, used to be so great and so helpful and this and that and one of the older ones got up and tapped him on the shoulder and said "What the hell are you talking about, how do you know, how do you possibly know what happened to us?, were we responsible?, could we decide what we were going to do, what goes on and doesn't go on? - why don't you just sit down!" He had got all that from his parents, you see - he'd inherited it unquestioningly. (Alan, former welfare worker)

Similarly, one social worker recognised that within younger generations of deaf people, attitudes towards social workers were more in line with mainstream professional relationships:

> There are a group of people who come in and are clear about what they want. I imagine that's very similar to young disabled people, they have much more of an idea about what they want to do, it's like they say "you're a social worker, you're here to assist me with x,y,z and this is what I want you to do". (Alice, social worker)

Examples were also given of situations in which the nature of service provision requested by deaf people was thought to no longer be justifiable by the professional:

> ...we always used to provide a duty social worker on Wednesdays and Saturdays and then we suddenly said "Why?" Why is this necessary, and who is feeling good out of this? Are we maintaining dependency? I mean we're talking in terms of empowerment, I think it's a horrible word but it's a word which is branded around a lot, it's jargony. We are almost creating a dependency. I missed it more than they missed me. I used to come along and perhaps do my duty in the duty book and then go for a beer. I think that deaf people perhaps didn't realise that your duty finished at 9 or whatever, they'd come in and have a beer and if you were still here at 11, they could come and see you as the duty social worker. It was almost an abuse. I was at one of the dances and someone started to say to me "Tax..." and I was thinking "bollocks to this, this is nonsense". Who is learning here? Pass the responsibility across, so there was quite hard adjustment from where I'd come from and that sort of over involvement, where it takes over your life. (Alan, former welfare worker)

> The other day someone said "you have to pay my bill for me every month, I can't do it because I forget". I said "sorry, but that's not my responsibility, it's your responsibility, it's not my job to sort out your bills". She was really angry and bitter that I wouldn't do it. But this is where my dilemma is - should I assist people who are going to be pissed of when I say it's not my responsibility, or should I say I'll do it? I feel like it goes against the grain of what I believe in to say "yeah, I'll pay your bills". (Laura, social worker)

While there was only cursory recognition for the fact that the professional body, for the most part created a state of dependency, there was acknowledgement of the role of deaf people in carrying forward this dependency.

7.10 Welfare Worker's Perceptions of Wellness in Deaf People

Before considering the influence of hearing professionals on the evolution on deaf wellness, it is important to consider direct references to health, specifically mental health. There was scant recognition of the existence of *different* cultural beliefs or behaviour for deaf people. This was perhaps linked to the perception, particularly by less experienced social workers, that the deaf people who frequented the deaf club, far from being core members of a cultural community, were only the most dependent and in need of help.

When asked what they considered most likely to affect deaf people's sense of wellness, within both groups of professionals, there was support for the belief that deaf people's well-being was exactly the same as hearing people's, and revolved around, for example, employment or relationships:

> The old missioners years ago said that deaf people are always happy, and I think that deaf people are no more happy than anybody else. There are deaf people who have chips on their shoulder but there are hearing people who have chips on their shoulder. There are deaf people who are paranoid, I mean some deaf people think that hearing people are always talking about them. I don't know if deaf people are more happy than anyone else. (Don, former welfare worker)

Wellness was rarely related to any positive deaf cultural experience, although there was recognition that being in control was significant to an experience of wellness:

> ...being given decent facilities and being allowed to control their lives. (Julian, social worker)

The need for language and communication was most often presented in compensatory terms for what remained primarily to be a devastating and isolating handicap.

Respondents were asked to describe their experience of mental health problems among deaf people. Their responses afforded the opportunity to compare perceptions of groups

of deaf people with additional needs visiting the deaf club, with those of deaf people themselves, presented in Chapter 6.

Welfare workers, as deaf people did (Chapter 6) recognised that those people with mental health problems, who had known each other prior to the onset of illness were treated with acceptance within the deaf community:

> We had an arrangement with the local mental hospital that they would bring down the four who were in the hospital on a Friday night, which was club night. They were always talked to, never ignored. They would go in and there was always a fag for them. The thing is, these four, of different ages had been to school with them so they were old school mates as well. (Jack, former welfare worker)

A common belief was that deaf people were limited in their understanding of illness. For example, behaviour which isolated a group of deaf people with additional disabilities was thought by hearing professionals to be a result of deaf people labelling as illness anything which diverted from the normal:

> You feel that the perception of certain groups is that they are nuts, not a normal group. In the deaf community if you have one or two people who are presenting themselves as different, then they must be ill. (Judy, social worker)

> I see them using the language that they are mentally ill but I don't know if they actually believe he's mentally ill or just a bit stupid or whatever I don't know. (Julian, social worker)

Chapter 6 reported that the exclusion of groups perceived to be unable to cope, for whatever reason could be seen to serve a purpose in reinforcing the experience of those deemed well. Patterns of acceptance and unacceptance, far from reflecting the workings of a complex cultural community, were often perceived by hearing professionals as resulting from ignorance or meaningless exclusion:

> You have to think about the distinction between mental illness and mental disability. I have certainly noted over the years that often the awareness doesn't distinguish between the two and I've seen it in the deaf club at a level that's really quite surprising. I don't think awareness is all that great but I would always expect it to be worse in the deaf community. (Fred, former welfare worker)

> I went to one (deaf club) a few years ago and I felt exactly the same thing. We were totally excluded and they actually said that they were deaf and they hadn't got learning

> difficulties and that the people we were with had learning difficulties first and were deaf second and they didn't want to be associated with learning difficulties. It was really hard work. The first time we went someone said "Oh, do you want to sit with these ladies?" and put out chairs a way away and it was really obvious that it was splitting the group. (Emma, social worker)

The deaf community is presented as being unkind to those with problems:

> I guess there are a lot of people who are lonely and the deaf community is not always kind to people who are lonely. The deaf community is not always kind to people who need to be encouraged so I suppose they don't show any reaction other than to ignore people. (Don, former welfare worker)

In summary, rigid beliefs about deaf people extended to a reluctance to recognise cultural differences in experiences of wellness. Hearing professionals maintained rigid views of what constituted deaf normality, that is, they believed that *all* deaf people were limited in their potential to be well. With this belief, there was little understanding of why deaf people may reject other deaf people.

7.11 Conclusion

Without any doubt the relationship between welfare workers and deaf people was immensely powerful. Much of their power, as we have seen, was sustained through their unique position in society. Knowledge of the nature of the deaf community and of the language of deaf people provided a crucial bridge to an otherwise isolated community.

Beliefs about deaf people often rested upon negative and disabling traits and in their most extreme form, justified paternalistic protection. In a less tangible way this situation served to sustain arguably inappropriate professional relationships. Although with reported reluctance, hearing parents and professionals often bowed to the welfare worker's power. Deaf people were similarly dependent upon welfare workers to negotiate the otherwise inaccessible and often daunting structures of daily life.

Clearly this situation was extremely powerful and in its nature was sustained both by deaf and by hearing cultures. Within the context of such powerful influences, of which hearing professional culture is perhaps the most powerful, we locate the construction of deaf wellness. In effect, guardians or gatekeepers of the deaf community put powerful

and dominating beliefs into practice, which assumed deaf people's limits, in terms of wellness. They sought to create 'meaning' for deaf people; however, in the process, suppressing the expression of meaning that deaf people might have created for themselves. Clearly within this climate cultural expression of both deafness and of deaf wellness was restrained.

This situation can be contrasted particularly with the experiences of the young deaf people in Study 3 (Chapter 6). While there was recognition of the symbolic power of hearing professionals, there was absolute certainty that to be well necessitated independence from outsider belief systems. Only in these circumstances could collective goals and strategies be established which assumed health and wellness to be a highly possible outcome.

Deaf cultural perceptions of wellness have been considered (Chapter 6) and one of the most powerful influences on that perception - hearing professional behaviour within the deaf community (Chapter 7). Chapter 8 will now return to deaf wellness, locating it both in relation to mainstream quantitative assessments of health and to knowledge about the impact of dominant cultural forces on the deaf cultural minority.

Chapter 8 Towards a Model of Deaf Wellness

8.1 Summary of Studies

Standardised diagnostic procedures revealed a dramatically higher rate of referral for psychiatric disorder among members of the Conrad Cohort against statistics for the general population (study 1). Of significance is the fact that while referrals for all types of illness were higher, a considerably greater proportion of deaf people within this sample were diagnosed as presenting with personality and behavioural disorders than comparative statistics for the hearing population.

The aims of Study 2 were twofold; firstly to explore the extent to which a high rate of mental illness was typical within the Conrad Cohort, and secondly to probe definitions of wellness among members. Standardised assessments of health (Study 2.1) suggest that the picture of mental health within the Cohort is more complex. The GHQ-30 and the SF-36 both registered high levels of behaviour normally associated with mental illness. However, within the same sub-sample of the Conrad Cohort, an exploration both of the perceptions of deafness, and of wellness (Study 2.2) suggested that quantitative assessments did not actually provide a full account of *wellness* behaviour within the same group.

Study 3 set out to explore the extent to which findings from Study 2 could be extrapolated to other groups within the deaf community. Focus groups with two groups of deaf people; deaf professionals and deaf students, explored deaf cultural perceptions of wellness. Together with findings from Study 2, a model of deaf wellness emerges.

In an attempt to trace the roots of this model of deaf wellness, Study 4 explored the suggestion that a deaf perception of wellness emerged, in part, in resistance to dominant ideological perspectives both of deafness and of mental health among deaf people. Interviews with hearing professionals illuminated beliefs and practices that would support this theory.

8.2 Deaf Wellness

Chapter 1 presents clear evidence that the deaf child's development is 'typically atypical' (Hoiting, Loncke 1990). For a deaf child born to hearing parents, virtually every key point of development, spanning most domains of life, is bestowed with challenges. Normal and healthy development depends on providing the child with the best possible support, in the most developmentally nutritious environment. However, such circumstances are often not achieved for deaf children, and healthy adult adjustment and mental health are often the casualties (section 2.2). While a developmental root to mental illness represents a more plausible aetiology to that which pathologises deafness itself. gaps were identified in our understanding of how the adult deaf person then goes on to perceive mental health and illness.

The picture of mental health within the deaf community is complex, and reflects diverse pathways from childhood to adult life. While previous research has often dwelt on the nature and extent of maladjustment, little attention has been directed towards attempts by deaf people not only to cope, but also to positively to seek out deaf wellness. This subject has been the focus of this research. From discussions, anchored in the life experiences of deaf and hearing people, emerged a theoretical model of deaf wellness which will be presented below.

The critical assumption in this research was that a full understanding of deaf people's experience of mental health is obtained when researchers draw on cultural perspectives, rather than relying exclusively on medical or social theories of health and illness. Only within this context may a theoretical model of wellness be introduced.

As a cultural construction, an essential element within the model is its relationship to the dominant cultural construction of deafness and mental health. Table 8.1 presents deaf wellness in relation to dominant notions of mental health and deafness.

DOMINANT HEARING IDEOLOGY	DEAF WELLNESS
1) Poor mental health is an inevitable outcome of deafness.	Wellness is a process as much as an outcome.
2) Deaf people experience a lower level of health to that which hearing people may expect.	Wellness occurs in a stable system. It does not require perfect health
3) Mental health symbolises a permanent state of stress-free functioning.	Deaf wellness means coping.
4) Mental health in deaf people is predicted by their deviance from hearing norms of health.	Deaf wellness is identified against that which is perceived, in deaf people, to be unwell.
5) Deaf people have the best chance of health if they are looked after by knowledgeable professionals.	Wellness is an expression of reclaiming deafness.
6) The isolation of deafness necessitates that deaf people associate with one another.	Deaf wellness is a celebration of deafness

Table 8.1 Features of dominant theoretical framework of mental health and deafness against features of the model of deaf wellness

8.2.1 Deaf wellness is a process as much as an outcome.

Wellness is described both as a process and as possessing properties of an outcome measure. Crucially, as a process, deaf wellness incorporates the possibility of change and transition.

Psychiatric theories are extremely powerful. The prevailing medical perspective links deafness and pathology, fixing ideologically dominant beliefs about normal and abnormal. The 'different' is taken to be both pathological and deviant. Within this framework it is no surprise that deaf people are more likely to be mentally ill. In addition, the expectation of illness, sustained by proponents of the dominant ideology, is satisfied.

Traditional points of reference in considering deafness and mental health have constituted measures of illness. Deaf people collectively are assessed in comparison to hearing people, and therefore are thought to be worse off in terms of mental health. Whether this outcome results from intrinsic pathology or of experience, a ceiling is placed upon the degree of mental health a deaf person is expected to experience.

However from this research, it is clear that for deaf people, the most meaningful points of reference for mental health were other deaf people, not hearing people. Furthermore, when respondents discussed aspects of their shared experience, they did not perceive their own mental health to be static, nor did they identify with the limitations placed upon their experience of mental health, by hearing professionals.

The recognition of deaf wellness as a *process* is set against the tendency in dominant culture to equate good mental health with achieving a positive healthy outcome. While allowances are made for slips and periods of mental distress, the goal of mental health is clear, and the hope is that the 'goal state' is maintained. In contrast, deaf people described the shifts they had to make away from influences they perceived to be threatening. At times, these shifts were shorter term, and reactive in nature, and at other times, shifts constituted longer-term responses, as in the emergence of coping strategies. By far the most profound and often dramatic shift, was away from the mother culture to cultural affiliation with other deaf people. This was specifically identified with a state of wellness.

Wellness necessitated engaging in such shifts, and awarding significance to the perception of wellness as a process as opposed to a 'well' static endpoint.

8.2.2 Deaf wellness represents system stability rather than perfect mental health.

Deaf wellness is presented not as a state of perfect mental health, but as state of system stability, or homeostasis.

A model of deaf wellness, first and foremost, does not deny the existence of mental illness, nor does it deny the fact that many more deaf people suffer from mental illness than do hearing people. However, while 'normal' distributions of health prevail, the deaf community is located at the lower end, peaking at a point below that for hearing people. While behaviour is awarded different significance by deaf and hearing people, such baselines obscure from a full understanding of mental health and illness and what it means to those who operate outside normal cultural constructions.

Certainly, from the data, a discrepancy emerges between quantitative data, collected using procedures standardised on normal populations, and the accounts of deaf people themselves. While comparative data succeeds in locating both deaf and hearing people in relation to a gold standard of health, deaf people's *wellness* behaviour is seriously misrepresented. For example, hearing standard measure assessments are sensitive to indicators of stress. A deaf cultural 'baseline' would assume a certain degree of stress and would rate the ability to cope or not with that stress as a positive indicator of adjustment. Furthermore, the recognition of a certain amount of stress actually appears to free the individual to negotiate the process of wellness. Those deaf people who attempted to 'pass' in hearing society demonstrated behaviour which disguised stress to such an extent that precarious coping mechanisms emerged.

Within this understanding, a state of perfect health, as anticipated by hearing people is not the goal of deaf wellness behaviour, rather wellness is expressed in the ability to negotiate and control a system which is constantly under assault.

8.2.3 Deaf wellness means coping.

The concept of coping is crucial in distinguishing those who have achieved deaf wellness from those who have not. If an individual can cope with stress, then the deaf community

recognises that he or she is well. Mental illness is therefore described, first and foremost, as a state in which an individual cannot cope.

For those outside the deaf community, the notion of coping appears to have several interpretations. Coping may be associated with low expectation, or of 'getting by' with something. As such, seeking merely 'to cope' may be thought to allude to the existence of internalised oppression among deaf people, a tradition of oppression having created low expectations among deaf people themselves with regards to mental health. Qualitative evidence suggests that this explanation may account for negative coping, however to deaf people a deeper significance is bestowed on the ability to cope.

Coping is also considered within a stress-coping framework, that is, as reactive behaviour that naturally seeks a dynamic equilibrium. While this may represent the status quo for hearing people, to many deaf people, a deeper and more positive significance is awarded to the expressed ability to cope. The knowledge of being able to cope constitutes a significant feature of the wellness identity.

Coping strategies may be positive or negative, active or inactive. Clearly negative coping, by its very nature may sustain a system that does not benefit the individual in an adjustive sense, despite being long term. This situation begs the question as to whether individuals in the latter category who demonstrate coping strategies, albeit negative, can be thought to experience deaf wellness? In response, there is a strong sense in which deaf wellness has several components, including a degree of identification with other deaf people. For the most part, individuals who described particularly inactive styles of negative coping (as it has been termed in this study) did not identify with their own deafness in any positive way, and, related to this, rarely desired contact with other deaf people. Positive coping, on the other hand, appears to have more adjustive qualities. While coping skills may not always be thoroughly effective, there is a conscious awareness that they nonetheless form part of a process that constitutes adjustment. In the same manner, wellness theory does not necessarily equate to a state of perfect health, but rather a collection of adjustive responses.

8.2.4 Deaf wellness is identified against that which is perceived, in deaf people, to be unwell.

Within a model of deaf wellness, respondents define wellness against characteristics deemed to represent an unwell state. An awareness of who is outside the central core of the deaf community, confirm the placement of those inside membership boundaries. Likewise, recognition of those who are perceived not to cope certifies the coping skills of those who are well.

To recap on the theoretical frameworks within which deafness and mental health have been understood, medical perspectives essentially register deviation from a normal state, which in deaf people has been symbolised by the notion of the deaf personality, or surdophrenia. Social perspectives, in contradiction, locate the causes of ill health predominantly within the social or developmental environment. It is only within cultural perspectives that explanations for an outcome of mental illness, question the suitability of normal states and standards.

Cultural perspectives on mental health within the deaf community prescribe an approach that supposes, first and foremost, that the expression and interpretation of mental illness is exclusive to different cultural communities. A model of deaf wellness takes this principle several steps further. Wellness behaviour is defined against 'ill' behaviour within the deaf community, rather than against any hearing standards. Consequently, wellness represents the opposite of that which is perceived to be unwell.

In the first instance, those who were well, acknowledged this location against those who were unwell. The designation of groups outside, however, holds a deeper symbolic value that has the effect of constituting a public statement of wellness. There is a need to reinforce the position of wellness by creating a distance and positively rejecting those who were unwell.

At this point, it is pertinent to take a step back to consider the evolution of the cultural deaf community. The testimonies of deaf respondents suggest that a significant aspect of becoming a culturally independent community is the rejection of oppressive structures in

which decisions are made by cultural outsiders as to who is well and who is ill. In this respect, consequences of moving from an oppressed state to an 'unoppressed' state are twofold, in that judgements are necessarily both strong and clear-cut, and also represent a public statement of autonomy.

A consideration of the exclusion of certain deaf people from insider membership of the deaf community illustrates this process. While the process of exclusion serves to confirm insider status and reclaim wellness on deaf terms, it appears to be harshly exclusive at times. For example, deaf people with additional needs are often designated outsiders and incapable of independent coping. Clearly this has implications for their potential or actual achievement of wellness. From the data it is also apparent that exclusionary tactics often emerge at the interface between traditional nurturing professional practice and more recent initiatives among deaf people to promote cultural independence and change. On the other hand, a need to reclaim wellness, necessitates the rejection of outsider attempts both to judge wellness, to dictate responsibility on to decide how to most appropriately make the individual well.

8.2.5 Wellness is an expression of reclaiming deafness.

In recognition that judgements are often made by outsiders as to the beliefs and behaviour thought to represent mental health in deaf people, the need to 'claim back' conceptual territory is identified. The process of reclaiming deaf wellness has necessitated identifying what deaf people themselves recognise to be well and unwell, placing certain groups firmly outside a constructed boundary of deaf wellness.

Medical perspectives on deafness constitute a common ideology within the medical and educational fields. The restitution narrative (Frank 1995), underlying medical perspectives, supposes that in their best interests deaf people should be 'repatriated' to hearing society. It is clear that such a culture of paternalism runs through many of the institutions that directly impact on deaf people's lives. An effect of this cultural climate is to constrain the expression of difference and of cultural deafness.

Increasing dissatisfaction among deaf people both to decisions made on their behalf and to the ideological structures that command them, has instigated growing resistance. Combined with the knowledge that most decisions are made by people who at least are cultural outsiders, and at worst are ill- or under-informed as to the nature of deafness and the deaf community, this resistance is felt strongly. The knowledge that deaf people often fundamentally disagree with beliefs and decisions concerning them only corroborates this dissatisfaction.

Cultural perspectives on deafness rest on the belief that the deaf community is a minority community, and in accordance with this belief, features of deaf wellness depart significantly from dominant notions of mental health. Deaf people's resistance may be framed as a process of reclaiming deafness.

The significance to deaf wellness is clear. Recognition of wellness relies on rejecting the goals and the associated practices of a dominant ideology of health and 'operationalising' their own independent perceptions of wellness.

8.2.6 Deaf wellness is a celebration of deafness.

Within a model of deaf wellness, wellness is created through the recognition and celebration of deaf culture, for example, through the common use of sign language or mutual recognition of identity.

Aspects of the deaf wellness model serve to distinguish those goals which others have set up on behalf of deaf people, from the goals which deaf people themselves identify with. A corresponding feature of deaf wellness is, therefore, to create new culturally independent definitions.

Features of a deaf wellness model draw very much from those things that are oppressed. For example the use of sign language in schools has traditionally been not only banned, but heavily stigmatised. The use of sign language is now presented as a point of reference in the celebration of deafness, and a central component in the definition of wellness. Strength and wellness at the level of the deaf community is rooted in a

recognition of the traits necessary for survival as an independent community, for example, the ability to cope, and to recognise a resilient deaf identity in one another.

Ultimately, deaf wellness can be seen as the celebration of deafness, and of those aspects of the experience of deafness which promote a sense of cultural identity and belonging.

8.3 Critical Discussion of the Model of Deaf Wellness

This research sought to explore the beliefs of members of the cultural deaf community. The construction of the model drew primarily from the experiences of members of the cultural deaf community. Just as experiences differ, for example, between different age groups and across different locations, so too it is anticipated that a model of deaf wellness will reflect the same diversity in expression.

Features of wellness are not clear-cut, in that those who could be described as well did not necessarily conform to each component of the model. In this respect the model constitutes a theoretical construction rather than a blueprint for the interpretation of beliefs and behaviour. In addition, it is not expected that the average deaf person identifies with deaf wellness as a conceptual basis for daily life. On the contrary, the research demonstrated that respondents did not immediately associate with the conceptual notion of wellness, rather basing their testimonies on the everyday experiences that motivate beliefs and behaviour.

It is appropriate to reiterate that theoretical conclusions were drawn from findings within the cultural deaf community. Study 2, (which explored the experience of mental health within a subsample of the Conrad Cohort) found many 'oral' deaf people who did not identify with the cultural deaf community and yet demonstrated high levels of association with other deaf people and a significant degree of wellness. They did not consider deafness to be a barrier to achieving health, and similarly relied on other deaf people to sustain them. These findings only serve to corroborate the principle tenet of wellness theory, that wellness must be understood within an appropriate cultural or experiential

framework. However, the experiences of oral deaf people were not fully explored in this research.

A central theoretical conclusion of this research is that membership of the cultural deaf community does not necessarily protect the individual from experiencing stress. However the ability to cope with stress and to develop strategies with which to respond to stress takes on enormous symbolic value, which contributes to deaf wellness behaviour. This finding differs from other views on cultural identity. For example Ridgeway (1997) concludes from her research that a strong deaf identity protected the individual from stress. Indeed, those with a strong deaf identity were less likely to experience mental health problems. While each body of research has a similar outcome, the emphasis of each differs. That is, while offering explanations for sustaining mental health, this research has yet to trace mental health outcome data among those who could be described as experiencing deaf wellness. Rather this study offers a theoretical framework within which to understand wellness behaviour.

8.4 Implications of the Model

These studies offer a new framework within which to explore mental health within the deaf community. In essence, the framework has emerged in response to perceived gaps in a traditional understanding of health and illness for deaf people. As such, implications of the research are far reaching. Traditional or dominant beliefs about deafness are woven into the fabric of most organisations established to provide services to deaf people. This has been evident in the treatment of BSL. While BSL is considered an inferior system of communication, at best offering clues to spoken English, deaf people will not be treated as minority language users. Deaf people themselves eagerly identify those areas of their life in which they have felt, at best, misunderstood, and at worst, oppressed. This clearly has implications for the status of a minority community, crucially affecting the power base with which deaf people access education, employment or the health services.

While it imperative to accept that cultural diversity exists and that deaf people do not necessarily share the same world view as hearing people, these studies have taken this

understanding one step further. In seeking to create a new style of response to understanding and working with the deaf community, it is necessary to allow new interpretative frameworks to emerge. A model of deaf wellness demonstrates a theoretical step in promoting this approach.

Returning to the mental health field, there are tangible implications of applying such an understanding to the delivery of mental health services. Research has demonstrated that the utilisation of health services is more closely linked to how people feel about health services, than to their actual medical condition. Specifically Mechanic (1962) states that people seek services most often when they perceive, within their own cultural frames of reference, that something is 'amiss' or on the judgement of significant others. This research has demonstrated that deaf people confirm their perceptions of health with other members of the cultural deaf community. While the culture of service delivery remains inappropriate, deaf people are likely be put off from seeking treatment for mental health problems. This issue may be seen in the context that deaf people are known to be under-represented as recipients of mental health services (Checinski 1991). Suspicion as to the culture of service delivery is potentially generated and affirmed at a community level leading to more widespread distrust of mental health services.

The issue of appropriate service delivery is increasing being challenged. In many spheres, notably the field of education, deaf people are slowly becoming service providers as well as service users. Their value as language consultants and role models has been recognised and steps implemented to ensure that deaf professionals are the norm rather than the exception. However, particularly within the mental health field, a new framework of understanding necessitates that deaf professionals become more prominent. That is, that while they may yet not possess equal professional qualifications, their leadership in the construction of frameworks of understanding is prioritised.

8.5 Future Research

These studies pave the way for future research. Four main strands of research have been identified.

1) While the model of deaf wellness evolved from deaf respondent's beliefs and experiences, it would be valuable to present the model back to representatives of the deaf community. While feedback mechanisms were employed in the initial processing of data, the validity of the model would be enhanced though renegotiation with deaf people.

2) While the model of deaf wellness emerged from discussion primarily with two groups of deaf people (Study 3, Chapter 6), it would be of great value to repeat the process with other groups of deaf people, reflecting diverse geographical and demographic locations and different experiences of deafness.

3) The model of deaf wellness, while fundamentally theoretical in construct, lends itself to practical application. While the need has been recognised to move beyond linguistic translation and towards cultural reconstruction, this may usefully be composed as a more tangible model. As such, its application to assessment and rehabilitation work within the field of mental health are clear.

4) Findings highlighted the dislocation both in attitudes and in beliefs between deaf people and hearing professionals. While each group collectively had strong views of the other, there was little reference to opportunities to appropriately explore this interface. Future research should encourage discourse between representatives of each group, which specifically explores this tension.

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APPENDIX 1

Study 2.2 Unstructured Interview Questions

Conrad Cohort Subsample

Conrad Cohort Subsample

Topic	Question	Probe	Tick
School	Type of school?	*Describe school – memories?* *Deaf/hearing? residential/day?*	
	Communication?		
	Qualifications?		
	Level of skill - satisfied?		
	Overall	*Expectations?/Aspirations?/* *'Contentedness'?*	
Work	Type of work	*Chosen how?*	
	Communication?		
	Social aspects?	*Quality of contact?*	
	Promotion prospects?	*Why?*	
Social	School peer group contact?	*Deaf/hear?Communication?*	
	Deaf community contact?	*When? How?*	
	Describe relationships?	*Fulfils expectations?* *Go to with problem?*	
Family	Structure?	*Describe family?* *Deaf/hearing?*	
	Communication?	*With different members?* *Feelings towards?*	
	Level of contact?	*[For what level of need?]*	
Deafness	How do you feel about being deaf (HOH)?	*Cope with deafness?*	
	Other deaf people have a hard time?	*Who? Why?*	
General	Doing what you expected to be doing ten years ago?	*Expectations, aspirations?*	

APPENDIX 2

GHQ-30 Schedule

General Health Questionnaire-30

Have you recently:

1.	been able to concentrate on whatever you are doing?	Better than usual	Same as usual	Less than usual	Much less than usual
2.	lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more
3.	felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
4.	felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable
5.	felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
6.	felt you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more
7.	been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
8.	been able to face up to your problems?	More so than usual	Same as usual	Less able than usual	Much less able
9.	been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more
10.	been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more
11.	been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more
12.	been feeling reasonably happy, all things considered?	More so than usual	About same as usual	Less so than usual	Much less than usual

13.	been managing to keep yourself busy and occupied?	More so than usual	Same as usual	Rather less than usual	Much less than usual
14.	been getting out of the house as much as usual?	More than usual	Same as usual	Less than usual	Much less than usual
15.	been feeling on the whole that you are doing things well?	Better than usual	About the same	Less well than usual	Much less well
16.	been satisfied with the way you've carried out your task?	More satisfied than usual	About same as usual	Less satisfied than usual	Much less satisfied
17.	been taking things hard?	Not at all	No more than usual	Rather more than usual	Much more than usual
18.	found everything getting on top of you?	Not at all	No more than usual	Rather more than usual	Much more than usual
19.	been feeling nervous and strung up all the time?	Not at all	No more than usual	Rather more than usual	Much more than usual
20.	found at times you couldn't do anything because your nerves were too bad?	Not at all	No more than usual	Rather more than usual	Much more than usual
21.	been having restless disturbed nights?	Not at all	No more than usual	Rather more than usual	Much more than usual
22.	been managing as well as most people would in your shoes?	Better than most	About the same	Rather less well	Much less we
23.	been able to feel warmth and affection for those near to you?	Better than usual	About same as usual	Less well than usual	Much less well
24.	been finding it easy to get on with other people?	Better than usual	About same as usual	Less well than usual	Much less well

25.	spent much time chatting with people?	More time than usual	About same as usual	less than usual	Much less than usual
26.	been finding life a struggle all the time?	Not at all	No more than usual	Rather more than usual	Much more than usual
27.	been getting scared or panicky for no good reason?	Not at all	No more than usual	Rather more than usual	Much more than usual
28.	felt that life is entirely hopeless?	Not at all	No more than usual	Rather more than usual	Much more than usual
29.	been feeling hopeful about your own future?	More so than usual	About same as usual	Less so than usual	Much less hopeless
30.	Felt that life isn't worth living?	Not at all	No more than usual	Rather more than usual	Much more than usual

APPENDIX 3

SF-36 Schedule

U.K. STANDARD SF-36 SAMPLE FORM

SF-36 HEALTH SURVEY

INSTRUCTIONS: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

(circle one)

Excellent 1

Very good 2

Good 3

Fair 4

Poor 5

2. Compared to one year ago, how would you rate your health in general now?

(circle one)

Much better now than one year ago 1

Somewhat better now than one year ago 2

About the same as one year ago 3

Somewhat worse now than one year ago 4

Much worse now than one year ago 5

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(circle one number on each line)

ACTIVITIES	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
a. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing **several** flights of stairs	1	2	3
e. Climbing **one** flight of stairs	1	2	3
f. Bending, kneeling, or stooping	1	2	3
g. **Walking more than a mile**	1	2	3
h. **Walking half a mile**	1	2	3
i. **Walking one hundred yards**	1	2	3
j. **Bathing or dressing yourself**	1	2	3

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(circle one number on each line)

	YES	NO
a. Cut down on the **amount of time** you spent on work or other activities	1	2
b. **Accomplished less** than you would like	1	2
c. Were limited in the **kind** of work or other activities	1	2
d. Had **difficulty** performing the work or other activities (for example, it took extra effort)	1	2

5. During the <u>past 4 weeks</u>, have you had any of the following problems with your work or other regular daily activities <u>as a result of any emotional problems</u> (such as feeling depressed or anxious)?

(circle one number on each line)

	YES	NO
a. Cut down the **amount of time** you spent on work or other activities	1	2
b. **Accomplished less** than you would like	1	2
c. Didn't do work or other activities as **carefully** as usual	1	2

6. During the <u>past 4 weeks</u>, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

(circle one)

Not at all 1

Slightly 2

Moderately 3

Quite a bit 4

Extremely 5

7. How much <u>bodily</u> pain have you had during the <u>past 4 weeks</u>?

(circle one)

None 1

Very mild 2

Mild 3

Moderate 4

Severe 5

Very severe 6

8. During the <u>past 4 weeks</u>, how much did <u>pain</u> interfere with your normal work (including both work outside the home and housework)?

(circle one)

Not at all 1

A little bit 2

Moderately 3

Quite a bit 4

Extremely 5

9. These questions are about how you feel and how things have been with you <u>during the past 4 weeks</u>. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the <u>past 4 weeks</u> -

(circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Did you feel full of life?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and low?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

U.K. STANDARD SF-36, BOOKLET FORM - PAGE FIVE OF FIVE

10. During the <u>past 4 weeks</u>, how much of the time has your <u>physical health or emotional problems</u> interfered with your social activities (like visiting with friends, relatives, etc.)?

(circle one)

All of the time 1

Most of the time 2

Some of the time 3

A little of the time 4

None of the time 5

11. How TRUE or FALSE is <u>each</u> of the following statements for you?

(circle one number on each line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get ill more easily than other people	1	2	3	4	5
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

APPENDIX 4

Study 2.2: Categories used for Analysis of Interviews (Conrad Cohort Subsample) using Ethnograph v4.0.

Conrad Cohort Subsample

1	**Accept**	Acceptance into deaf community
2	**Childhood**	Reference to childhood
3	**Communic**	Reference to communication
4	**Coping**	Reference to coping
5	**Cult.Isol**	Cultural isolation
10	**DCom.Cont**	Deaf community contact
11	**Deaf**	Reference to deafness
12	**D.Club**	Deaf club
13	**DCom.PCont**	Deaf community point of contact
15	**Deaf.Fam**	Deaf people from deaf families
16	**Deaf/Hear**	Deaf and hearing identities
17	**Dual**	Dual identity
18	**Hear.Fam**	Deaf people from hearing families
19	**ID.**	Reference to identity
20	**Isol.Com**	Reference to isolation relating to communication
21	**Isol.Cons**	Consequences of isolation
22	**Int.Work**	Integrated work situation
23	**Isol.Deaf**	Reference to isolation due to deafness
24	**Isol.Work**	Isolation of deaf people at work
25	**Oral**	Influence of oralism
26	**Parents**	Reference to parents
27	**Role**	Reference to role models
28	**Suffering**	References to suffering

APPENDIX 5

Study 3 Focus Group Schedule

Deaf Professionals, Session 1

Focus Group 1 – Deaf Professionals

Introduction

-structure

-timing

-confidentiality

-use of materials

Stimulus 1

I rarely go to deaf clubs, but I have been involved in work with deafness for 20 years and have deaf friends so I have support. But what about the others? Where do they get their support from? This has mental health implications. Good mental health is about having a balance in life. Having adequate emotional sustenance from those close to you, from those who are friends and who are work colleagues. Having time off for relaxation and having some way of releasing all the tensions of life are all important. If you are deaf and do not feel that you can get support from your hearing colleagues and I have to say, many deaf people do not feel supported by their hearing colleagues - and if you don't get support from your old friends in the deaf club, then where do you get it from?

Questions

- Is this a realistic way of thinking about mental health?

- Is 'full health' possible in a hearing environment?

- How are things different for deaf people brought up in a hearing/deaf family?

(probe: transition period)

- Describe a well person to me

(probe: differences for deaf/hearing people)

- Who is well?

(probe: describe a well person)

APPENDIX 6

Study 3 Focus Group Schedule

Deaf Professionals, Session 2

Focus Group 2 – Deaf Professionals

Introduction

-structure

-timing

-confidentiality

-use of materials

Stimulus 1

B had been born profoundly deaf. He was educated in a residential school for the deaf which adopted an oral only approach. When he left school he had only limited verbal language and poor academic achievements. B communicated in sign language and finger-spelling. After leaving school B worked first in a bakery and later he helped deliver milk.

B's family had difficulties communicating with him and he had few friends. He was said to be irritable at times, especially under the influence of alcohol. He drank a lot and was often drunk.

He complained that everywhere he walked he was followed and that when he stopped, those following him also stopped. He did not know who they were or why they were following him. He thought that the people who were following him were from London where a deaf girl named Molly, a school mate, was living. He thought that he had been feeling like that for about two years. Sometimes he felt 'mixed up'. He reported having seen Christ.

Questions

- Is this person mentally ill?

(probe: why? which aspects of behaviour?

- How would you respond to this type of behaviour in a public situation?

- How would your behaviour differ if you were in the deaf club?

(probe: community response? other different situations?)

What would his position be in the deaf community?

Stimulus 2

M was a 20 year old profoundly deaf man. He was admitted as an emergency to the psychiatric department of a general hospital one evening under the assessment order of the Mental Health Act, after assaulting his father.

The police had been called to his home whereupon he became so disturbed that he had been handcuffed to get him into an ambulance. Without verbal skills, M communicated very well in sign language. He later explained that he had become upset following a difference of opinion with a workmate. He was afraid that as a consequence he might loose the only friend at work. On the way home he felt depressed and had gone to the pub for a few pints.

When he arrived home his parents noticed there was something wrong. He tried to explain, but communication between them was poor. He became frustrated and angry and left the room, slamming the door. He father had followed him and had taken hold of him from behind. He was shocked and angry and struck his father. He was very sorry for what had happened.

Questions

- Is this person mentally ill?

(probe: why? which aspects of behaviour?)

- How does his behaviour relate to the idea of 'coping', brought up in the last session.

- Can he **become** well?

(probe: how long will it take? what are the conditions?)

Stimulus 3

F, a 22 year old woman was referred to a consultant psychiatrist for assessment and treatment. She had been admitted to a psychiatric hospital some 12 months earlier. It was said that nobody there could communicate effectively with her.

F became profoundly deaf in early childhood as a result of illness and at the age of 6 acquired a physical disability. She had been educated at a residential school for the deaf. F left school at 16 and entered a residential centre for those with a physical disability. At 21 she went into hospital for an operation. After this she became 'moody and difficult'. Those who worked at the centre described her as an immature woman who reacted to minimal stress with aggressive behaviour. Her psychiatric report used the terms 'dull' and 'backward' to describe her.

She said she disliked the hostel and wanted a flat of her own. The social worker, although sympathetic, considered that both her low intelligence and additional disability prevented her from living independently.

Questions

- Is this person mentally ill?

(probe why? which aspects of behaviour?)

- What areas of the story can you personally relate to?

- What normally happens in cases like these?

- How are things usually dealt with by professionals?

APPENDIX 7

Study 3: Categories used for Analysis of Focus Group Discussion (Deaf Professionals) using Ethnograph v4.0.

Deaf Professionals

1	**Accept**	Acceptance into deaf community
2	**Add.Needs**	Additional needs (to deafness)
3	**Audism**	Reference to audism
4	**Bound**	Reference to boundaries
5	**Childhood**	Reference to childhood
6	**Communic**	Reference to communication
7	**Coping**	Reference to coping
8	**Cult.Isol**	Cultural isolation
9	**DCom.Cont**	Deaf community contact
10	**Def.**	Definitions of mental illness
11	**Deaf**	Reference to deafness
12	**D.Club**	Deaf club
13	**DCom.PCont**	Deaf community point of contact
14	**Deaf+Deaf**	Deaf people working/living together
15	**Deaf.Fam**	Deaf people from deaf families
16	**Deaf/Hear**	Deaf and hearing identities
17	**Dual**	Dual identity
18	**Fam.Diffs**	Differences between deaf and hearing families
19	**Hear**	Reference to hearing influence
20	**Hear.Fam**	Deaf people from hearing families
21	**ID.**	Reference to identity
22	**Isol.Com**	Reference to isolation relating to communication
23	**Isol.Cons**	Consequences of isolation
24	**Int.Work**	Integrated work situation
25	**Isol.Deaf**	Reference to isolated due to deafness
26	**Isol.Work**	Isolation of deaf people at work

27	**Label**	Reference to labeling
28	**Men.Health**	Reference to mental health
29	**Oral**	Influence of oralism
30	**Parents**	Reference to parents
31	**Per.Aet**	Perceived aetiology of MHP
32	**Reaction**	Reaction to outsider groups
33	**Role**	Reference to role models
34	**Structure**	Reference to structure of the deaf community
35	**Treat**	Treatment (of MHP)
36	**Well**	Reference to wellness

APPENDIX 8

Study 3 Focus Group Discussion Schedule

(Deaf Young People)

Focus Group – Deaf Young People

Introduction

-structure

-timing

-confidentiality

-use of materials

Questions

-Childhood:

memories?

communication/access?

-School:

type of school(s) attended:

deaf/hearing

residential/day

communication method?

teachers?

(probe: memories, feelings towards, changes as they approach adulthood)

- Deaf Community:

contact?

(probe: when? transition? or abrupt/gradual feelings towards?)

-Identity:

deaf/hearing? - (either or both)

(probe: friends - which?, comfortable where?, changed over time?)

-Work:

expectations?

-Health:

feel healthy? - describe a healthy person?

-Mental health:

know anyone who is mentally ill?

(probe: describe them? why are they ill/what made them ill? can they get better? how?)

APPENDIX 9

Study 3: Categories used for Analysis of Focus Group Discussion (Deaf Young People) using Ethnograph v4.0.

Deaf Young People

1	**Accept**	Acceptance into deaf community
2	**CI**	Reference to cochlear implants
3	**Communic**	Reference to communication
4	**Com.Def**	Definition of the deaf community
5	**Culture**	Definition of deaf culture
6	**D.Club**	Deaf club
7	**DCom.PCont**	Deaf community point of contact
8	**Deaf**	Reference to deafness
9	**Deaf+Deaf**	Deaf people working/living together
10	**Deaf.Fam**	Deaf people from deaf families
11	**Deaf/Hear**	Deaf and hearing identities
12	**Expect**	References to self-expectation
13	**Hear**	Reference to hearing influence
14	**Hearing**	Attitude to hearing people and situations
15	**Hear.Fam**	Deaf people from hearing families
16	**ID.**	Reference to identity
17	**Isol.Com**	Consequences of isolation
18	**Isol.Cons**	Consequences of isolation
19	**Label**	Reference to labeling
20	**Oral**	Influence of oralism
21	**Parents**	Reference to parents
22	**School**	Reference to school
23	**SL**	Sign language
24	**Structure**	Reference to structure of the deaf community
25	**Youth**	Reference to older generation

APPENDIX 10

Study 4 Unstructured Interview Schedule

(Hearing Professionals)

Hearing Professionals

Topic	Question	Probe	Tick
Background:	Reason for working in the field?		
	Training and work experience?		
Relationship with Deaf Community:	How well do you feel you know the deaf community in your area?		
	Satisfaction with level of signing?		
	Adjectives you would use to describe your role?		
	Satisfaction with job?	*Describe job*	
Health	How would you judge if a deaf person had a mental health problem?		
	Experience of diagnosing mental health problems in deaf people?		
	How would you describe your learning about this?		
	Evidence for prevalence of mental health problems in deaf people?		
	Certain types of problems more prevalent than others?	*Same kinds of problems as hearing people? Different how?*	
	Causes of mental health problems within the deaf community?		
	Deaf people's reaction to mental health problems within deaf community?	*Good understanding? Supports*	

		people?	
Wellness	People that you work(ed) with 'happy'?	*Other deaf people you know?*	
	What makes deaf people unhappy?	*Easier/harder for deaf people to be happy?*	
	What do deaf people do when they are well/unwell?		
	Deaf people capable of the same degree of happiness as hearing people?		
Professional Role	Social workers closer to the deaf people they work with than other professionals e.g. doctors, teachers, community leaders?	*If not, who is?*	
	'In order to be happy, deaf people need a certain amount of help from outside agencies' - agree?		

APPENDIX 11

Study 4: Categories used for Analysis of Interviews (Former Welfare Workers) using Ethnograph v4.0.

Former Welfare Workers

1	**ab/norm**	Reference to ability to judge normal or abnormal behaviour etc. in deaf people
2	**bridge**	Missioner/welfare worker as bridge between deaf and hearing
3	**b/w**	Deaf people's black and white thinking
4	**comm**	Reference to communication
5	**comp.cap**	Reference to deaf people's competence and capability
6	**d.club**	Reference to deaf club
7	**d.com**	Views on deaf community
8	**deafdis**	Deafness as a disability/deprivation
9	**dep**	Deaf people's dependence on missioners
10	**d.fam**	Differences between those from deaf and hearing families
11	**diff**	Difference between traditional 'missioner' and those interviewed
12	**edu**	Reference to deaf people's education.
13	**ego**	Reference to egocentricity
14	**future**	Perceptions of the future
15	**health**	Reference to deaf people's health
16	**hear**	Comparisons to hearing people
17	**MHD**	Reference to deaf people's views on mental health
18	**MHM**	Missioner/welfare worker's view of deaf people and mental health
19	**motive**	Reference to missioner/welfare worker's motive
20	**per.mis**	Reference to deaf people's perception of missioner/welfare worker
21	**power**	Reference to missioner/welfare worker's power

22	**reaction**	Reaction to missioner/welfare worker's attempts to devolve power
23	**resp**	Reference to deaf people taking responsibility
24	**shepherd**	Direct/indirect reference to missioner/welfare worker as 'shepherd'
25	**susp**	Responsibility to suspiciousness
26	**SW**	Views on the social work system now
27	**task**	Reference to missioner/welfare worker's 'task'
28	**trans**	Reference to transition and change

APPENDIX 12

Study 4: Categories used for Analysis of Interviews (Social Workers) using Ethnograph v4.0.

Social Workers

1	**ab/norm**	Reference to ability to judge normal or abnormal behaviour etc. in deaf people
2	**bridge**	Welfare worker/social worker as bridge between deaf and hearing
3	**b/w**	Reference to black and white thinking
4	**comm**	Reference to communication
5	**comp.cap**	Reference to deaf people's competence and capability
6	**d.club**	Reference to deaf club
7	**d.com**	Views on deaf community
8	**deaf/hear**	Deaf/hearing professional relationships
9	**dep**	Deaf people's dependence on welfare worker/social worker
10	**diff**	Difference between 'welfare worker' and those interviewed
11	**edu**	Reference to deaf people's education.
12	**ego**	Reference to egocentricity
13	**extra**	Reference to deaf people's 'extra' compensatory abilities
14	**health**	Reference to deaf people's health
15	**hear**	Comparisons to hearing people
16	**immat**	Reference to immaturity
17	**MHM**	Welfare worker/social worker's view of deaf people and mental health
18	**MHP**	Reference to deaf people's view of mental health
19	**mission**	Views on the missioner/welfare system
20	**money**	Reference to deaf people and money
21	**motive**	Reference to welfare worker/social worker`s motive

22	**per.mis**	Reference to deaf people's perception of welfare workers/social worker
23	**power**	Reference to welfare worker/social worker's power
24	**reaction**	Reaction to welfare worker/social worker's devolution
25	**resp**	Reference to deaf people taking responsibility
26	**rel**	Hearing professional/deaf client relationship
27	**shepherd**	Direct/indirect reference to professional as 'shepherd'
28	**society**	Perception of societal reaction to deaf people
29	**susp**	Responsibility to suspiciousness
30	**SW**	Views on the social work system now
31	**task**	Reference to welfare worker/social worker's 'task'
32	**trans**	Reference to transition and change

APPENDIX 13

Sample of Ethnographic Content Analysis Coded Printout

EARCH RESULTS 10/15/1996 1
EARCH CODE: ISOL.CONS

.:YING I was taug

: #-HEAR.FAM #-PARENTS

SEARCH CODE: ISOL.CONS

;-DEAF $-ISOL.CONS

: I was taught Sign Language. All my 83 | -$
: life IÆve had problems 84 | $
: communicating with hearing people. 85 -# $
: Some I can understand and some I 86 $
: just canÆt. I get fed up always 87 $
: having to write notes and repeat 88 $
: myself again and again. So I went 89 -$

A:YING 6- I thin

SEARCH CODE: ISOL.CONS

#-PARENTS #-HEAR.FAM #-ISOL.COM #-ISOL.CONS

: 6- I think there were some stressful 107 -#
: situations, I mean my mother signed 108 #
: and used to interpret for me but my 109 #
: father never signed, and neither 110 #
: did my brother. I would sit there 111 #
: watching them talking and I 112 #
: wouldnÆt have a clue what was going 113 #
: on. IÆd keep on nagging my mother 114 #
: to tell me what they were saying 115 #
: and IÆd get so stressed out. I 116 #
: really wish theyÆd learnt to sign. 117 -#

A:YING 4- Normall

SEARCH CODE: ISOL.CONS

#-HEAR.FAM #-ISOL.COM #-DEAF #-ISOL.CONS

: 4- Normally it isnÆt too bad in my 154 -#
: family, because they can all sign, 155 #
: but I remember once when my 156 #
: grandparents came to stay; it was 157 #
: Christmas. It was so stressful 158 #
: around the table, horrible, you get 159 #
: so fed up. 160 -#
